

Disability in Person with Total Laryngectomy: A WHODAS 2.0 Perspective

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18SLP018

**This Dissertation is submitted as part of fulfilment for the Degree of
Master of Science in Speech Language Pathology
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**All India Institute of Speech and Hearing
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July, 2020

Dedicated

To Umma & Uppa

&

To My Remarkable Guide

Certificate

This is to certify that this dissertation entitled “**Disability in Person with Total Laryngectomy: A WHODAS 2.0 Perspective**” is the bonafide work submitted as part of fulfilment for the Degree of Masters of Science in Speech Language Pathology of the student with Registration No. 18SLP018. This has been carried out under the guidance of a faculty of this institute and has not been submitted earlier to any other Universities for the award of any other diploma or degree.

Mysuru
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Certificate

This is to certify that this dissertation entitled “**Disability in Person with Total Laryngectomy: A WHODAS 2.0 Perspective**” has been prepared under our supervision and guidance. It is also certified that this has not been submitted earlier to any other Universities for the award of any other diploma or degree.

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Declaration

This dissertation entitled “**Disability in Person with Total Laryngectomy: A WHODAS 2.0 Perspective**” is the result of my own study under the guidance of Mr. Freddy Antony, Assistant Professor in Clinical Psychology and co-guidance of Dr. Jayakumar T. Associate Professor in Speech Science, All India Institute of Speech and Hearing and has not been submitted earlier to any other Universities for the award of any other diploma or degree.

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Abstract

Laryngectomy is a surgery performed to remove the larynx in advanced stages of laryngeal cancer. It has detrimental effect on an individual's personal, social and work life leading to disability. To provide a standardized measure for health and disability across cultures, the WHO has developed WHODAS 2.0. The aim of the study is to determine the extent of disability in person with aphonia secondary to total laryngectomy using (a) measures as suggested by the 2018 RPWD Act Guidelines and (b) self-administered 12-item WHODAS 2.0 version. It also aimed to investigate the influences of various socio-demographic and treatment related clinical variables on disability scores. There were 19 individuals, (18 males and one female) in the age range of 40 to 80 years, with aphonia secondary to total laryngectomy in the study. The findings revealed that the percentage of disability under the RPWD Act Guidelines 2018 was a constant 100% for all participants. On the other hand, the mean disability population score of WHODAS 2.0 was 91.44 (SD=8.83). With reference to the pattern of disability, participation in community activities and emotional health were the most affected and cognition and learning were the least affected. Out of all the sociodemographic and treatment related clinical variables analysed, only monthly percapita income had a correlation with the WHODAS 2.0 total score. Also, age and family size of the participants were associated with disability scores. Results suggest that disability is not merely a health issue. It is a complex phenomenon, reflecting the interaction between the characteristics of a person's body and the characteristics of a society in which he or she lives.

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Chapter 1

Introduction

Chronic diseases lead to a negative impact on the well-being of individuals. Laryngeal cancer is one such chronic illness. Laryngectomy - a surgery performed to remove the larynx in advanced stages of laryngeal cancer- has a detrimental effect on an individual's personal, social, and work life. These effects lead to disability. Disability is a significant concern that can result in reduced efficiency, increased costs and higher turnover.

1.1 The Biomedical Model of Illness

The biomedical model suggests that illnesses are biologically dependent diseases. It is the dominant disease model today. It implies that diseases are entirely by deviations from the observable biological variables' standard. This leaves no place for the psychological behavioural and social aspects of disease within its context (Deacon, 2013). Not only does the biomedical paradigm involve treating illness as an agent independent of social behaviour, but it also involves describing behavioural abnormalities based on disordered somatic (biochemical or neurophysiologic) processes. For example, in case of mental disorders, the biomedical model reduces the impact of psychosocial factors to mental disorders and believes that psychological phenomenon can completely be minimised to their biological origins by the eliminative reductionist position (Lilienfeld, 2007). Any disorder is, in its core, a biological process (Meyer, C., & Davis, S., 2003).

1.2 The Biopsychosocial Model of Illness

The biopsychosocial model is an interdisciplinary approach that explores how biology, psychology, and socio-environmental aspects connect to each other. The model precisely explores how these factors play an important part in the human

development of different health and disease models. It was first developed by George L. Engel in 1977 to employ such complex thought. It continues to bear influence in psychology, wellness, medicine, and human development. Contrary to the biomedical approach, Engel proposed a more holistic approach by recognising that each patient has its own opinions, emotions, and history. The model has been framed both for diseases and psychological issues. The biopsychosocial model represents disease development using the dynamic combination of biological factors (biochemical, genetic, etc.), psychological factors (temperament, mood, actions, etc.) and social factors (socio-economic, family, cultural, medical, etc.) (Engel 1980 The Clinical Application of the Biopsychosocial Model.Pdf, n.d.). For example, a person may have a genetic predisposition for stuttering, but he must also have social factors such as severe stress at work and family life, and psychological factors such as a perfectionistic propensity to cause this genetic code for stuttering to manifest. An individual may have a genetic predisposition to a disease, but it must be caused by social and cognitive factors.

1.3 The Diathesis-Stress Model

The proposed model for diathesis-stress suggests that predisposing factors interfere with trauma experience and set several behavioural and cognitive mechanisms in motion. The following variables are included in the model in particular: vulnerability to fear, the anticipation of pain, catastrophic ideation, self-efficacy, attributions about the cause of symptoms and potential concerns, operant conditioning and fear-avoidance beliefs (Turk, 2002). This collection of variables may be crucial to recognise physical disability's persistence. It is important to note that these causes are interfering with the trauma and any related physical pathology. It does not necessarily mean that physical aspects are irrelevant, but rather that these

conditions and persons with these conditions are perceived from a bio-behavioural viewpoint. Some people resume their normal activities in due course following injury and discomfort and recover. Under the diathesis-stress model, disability can grow from the interaction of predisposing factors (diathesis) and threatening environmental events (stress) and be aggravated and sustained. Thus, people who are emotionally sensitive and susceptible to fear (diathesis) may be more likely to acquire responses to avoidance following a physical trauma (a stressor that generates fear).

1.4 Illness and Disability

Understanding what disease a patient has, helps in the process of formulating strategies for intervention and to predict results and outcome to an extent. However, diagnosing a condition is not enough to fully understand the patient and their experience in life. The important aspect is one's routine activities and the work necessary to fulfil his or her roles in different social areas.

Even though the disability part is taken into consideration by the professionals, there is a lack of consistency in the areas they consider. According to the World Health Organization (2000), disability is a major health issue. When the burden of disease is assessed, more than 50 percent of the weight of premature mortality is due to overall disability. When a person's daily routine and activities are limited, the case is considered clinically significant. Information regarding disability serves as a basis for evaluation and planning. As disability affects interactions between the people and their surroundings in different life events, it is crucial to define and quantify disability.

1.5 Disability in person with aphonia secondary to total laryngectomy

According to guidelines issued by the Department of Empowerment of Persons with Disabilities, GOI (2018), disability in speech and language refers to permanent disability from conditions such as laryngectomy affecting one or more aspects of speech and language due to any neurological or organic causes. In total laryngectomy procedure, removal of all of the cartilages, the hyoid bone, and the pre-laryngeal muscles are involved. The stoma is created by suturing the end of the trachea to the skin of the neck.

Laryngectomy is the surgical removal of the larynx and the airway separation from the mouth, nose and oesophagus. There are a few types of laryngectomy surgeries, including partial and total laryngectomy.

A portion of the larynx is removed in partial laryngectomy,. A temporary tracheostomy may be mounted, which may be removed later. In total laryngectomy, the entire larynx is removed. To create a new way of breathing a permanent stoma (tracheostomy) is created. This may include the removal of a portion of the pharynx, some surrounding muscles and some lymph nodes.

Total laryngectomy is a significant procedure of the head and neck often performed for advanced laryngeal cancer. While this form of radical surgery can be life-saving, it has major consequences for a patient. The detachment of the airway from the nose, mouth and oesophagus leads to a lack of ability to speak and the termination of the pharyngeal and nasal segments from the lower airways, resulting in altering of the breathing system and loss of active smelling.

Patients must get conditioned with the stoma and the associated consequences. Since the loss of normal speech is the most crucial effect of a person with laryngectomy, total laryngectomy has always been associated with attempts to restore patients' speech. The voice plays a significant role in one's identity and contributes significantly to the patients' overall quality of life. As a result, patients may feel the loss of their voice as a loss of part of their identity. A study on quality of life in patients with head and neck cancer reported substantial decrements in general functional status, communication, eating, emotional well-being, pain and other quality of life scales (Taylor et al., 2004).

1.6 The WHODAS 2.0

A project by the WHO (World Health Organization, 2001) on the topic Assessment and Classification of Human Functioning, Disability, and Health represented many researchers, over 100 countries and consumers in international collaboration. As a result, the International Classification of Functioning, Disability, and Health (ICF) as a consensus framework was formed. The ICF defines its operational assessment by taking every person's function at the body, person, or society level into consideration. It describes disability as a diminution in each functioning domain (World Health Organization, 2001). However, ICF is not a practical tool for disability assessment in clinical practice on a daily basis. Therefore, WHO came up with the "WHO Disability Assessment Schedule" (WHODAS 2.0) to address the necessity, and offer a standardised health and disability measure across different cultures (WHO | The World Health Report 2001 - Mental Health: New Understanding, New Hope, n.d.). The World Health Organization Disability Assessment Schedule (WHODAS 2.0) is a popular and highly reliable self-report questionnaire that measures disability over the past 30 days (Ustün et al., 2010).

However, it remains indistinct whether the WHODAS 2.0 is an effective measure of disability in patients with total laryngectomy. A complete outline of the disability in total laryngectomy also requires a review of socio-demographic and treatment-related clinical variables that may represent varying levels of disability reported.

The WHODAS 2.0 12-item version takes only 5 minutes to administer and has been used in many population-level surveys to get scores for six domains (Cognition, Mobility, Self-care, Getting along, Life activities and Participation) of functioning (Ustün et al., 2010). It is free of cost and is available to the public (Ustün et al., 2010). It measures the general functioning, consistent with the WHO theory that functional disabilities are distinct from disorders, unlike the Global Assessment of Functioning Scale (Hall, 1995), which rated the effects of mental illnesses in daily lives (American Psychiatric Association, 2013; Ustün et al., 2010).

The WHODAS 2.0 incapacity scores across socio-demographic features, various conditions, relevant severity levels and normative values need to be established (Gold, 2014; Konecky et al., 2014). Besides, assessment of disability is frequently requested by legal, welfare and administrative sources. Thus, the aim of the study is to determine the extent of disability in person with aphonia secondary to total laryngectomy.

1.7 Objectives

- To assess and find the extent of disability in person with aphonia secondary to total laryngectomy using the WHODAS 2.0.
- To assess the percentage of disability in person with aphonia secondary to total laryngectomy using RPWD Act Guidelines 2018.

- To determine how the scores of RPWD Act Disability is correlated with six subdomains of the WHODAS 2.0.
- To examine the influence of socio-demographic and treatment-related clinical variables on scores of disability.

Chapter 2

Literature Review

2.1 Studies on Laryngectomy

Laryngeal cancer is the second most common carcinoma of the head and neck. It accounts for around 2.4% of all newly diagnosed malignancies globally every year. Most of these carcinomas are squamous cell carcinoma, responsible for 85 to 95 per cent of laryngeal malignancy (Jemal et al., 2007). Laryngeal cancer occurs more often in males than in females (Baselga, 2002). The pathogenesis of laryngeal cancer has included multiple risk factors. Tobacco and alcohol consumption are the most significant of these (Cann, 1980). Exposure to many other environmental factors, such as textile dust, polycyclic aromatic hydrocarbons, and asbestos, is thought to potentially raise the risk of laryngeal cancer (Stell & McGill, 1973).

The guideline recommendation for the treatment of advanced laryngeal cancer has classically been surgery (Forastiere et al., 2008). However, despite all the possible explanations, some patients opt for non-surgical treatment. But, there are very high risks of recurrence which would ultimately require surgery. Surgical treatment of advanced cancers of the larynx often requires total laryngectomy (Chaturvedi et al., 2013). Over the years, the prognosis of laryngectomy remained fairly good, with survival rates of 65-75 percent for five years (Manni et al., 1992). The procedure does have different functional and physiological consequences. Besides the loss of voice, there is a lack of sense of smell, weak cough reflex, difficulty swallowing, changes in lung function and problems associated with a permanent tracheostoma (Nawka & Hosemann, 2005). The main concern of head

and neck surgeons and speech-language pathologists has been the functional treatment of laryngectomy patients. Various speech rehabilitation has led to improvements in those patients' quality of life.

2.2 The WHODAS 2.0.

There are many versions of the WHODAS 2.0. There are 36 questions in the complete version, and 12 questions in the shorter version. The complete WHODAS 2.0 36-item version was developed by choosing objects based on the psychometric technique of the item-response theory (IRT) (Ustün et al., 2010). It takes 20 minutes of administration to get scores for six domains of functioning (Ustün et al., 2010). In comparison, the short 12-item version uses a subset of the main questions, including two from each feature domain, which accounts for 81 percent of the 36-item version variance (Ustün et al., 2010). The shorter version can be administered in 5 minutes (Ustün et al., 2010). Routine performance evaluation is increasingly being used to monitor service performance, and the WHODAS 2.0 plays a role in that.

2.3 Studies using the WHODAS 2.0.

Visual impairment (VI) and hearing impairment (HI) contribute to varying everyday limitations. Chang et al. (2018), using the ICF, measured the level of functioning in patients with VI or HI. This cross-sectional national analysis included 312 individuals with VI and 540 individuals with HI. Using the WHODAS-2.0, each individual's degree of functioning and disability was measured. The degree of restriction linked positively to the level of Visual Impairment. Specifically, individuals with VI were likely to encounter obstacles to accessing products for mobility, education and communication. Scores of the WHODAS 2.0 were strongly correlated with the severity of VI. Referral and treatment of Mild VI should be

aimed at the earliest possible opportunity. Compared with HI patients, VI patients experience obstacles to exposure to environmental factors more often.

According to James & Mukundan (2017), the psychosomatic symptoms integrated into the WHODAS 2.0 can be used on tinnitus subjects to assess their status and condition within the context of the ICF. The reliability of internal consistency was satisfactory for all the WHODAS 2.0 domains with a moderate to high domain-total correlation, except for mobility and self-care. It was concluded that interpersonal life activities, cognition and participation domains of the WHODAS 2.0 are relevant and vital and can, therefore, be used in tinnitus assessment batteries.

Another study (Habtamu et al., 2017) aimed to assess the validity and psychometric properties of the WHODAS 2.0 in individuals diagnosed with severe mental disorders and their significant others. To evaluate comprehensibility, cognitive interviews were conducted with 20 patients and 20 caregivers. Internal consistency of the overall scores and domain scores ranged from very good to outstanding. The WHODAS 2.0 scores were strongly correlated with a locally defined function index, and moderately with the severity of clinical symptoms. It was sensitive to treatment changes also. The six subscales, as predicted, loaded heavily on the general impairment element, and every item loaded substantially onto their respective domains. The factor loadings of every item in the one-factor model of the WHODAS 2.0 12 items version were also high. When the data from the caregivers was analysed, both the full and short versions had identical psychometric properties, except higher mean values and greater sensitivity to shifting. Habtamu concluded that both the WHODAS 2.0's 12 and 36 item versions have acceptable psychometric and validity properties and can be used as a cross-cultural measure.

Sjonnesen et al. (2016) conducted research using data from the 2012 Canadian Community Health Survey – Mental Health portion (CCHS-MH) to assist Canadian psychiatrists in evaluating the WHODAS 2.0 as a potential substitute for the Global Assessment of Functioning Scale (GAF). Diagnoses of schizophrenia, depression, bipolar I disorder, generalised anxiety disorder (GAD), major depressive episode (MDE), substance abuse/dependency, and alcohol abuse/dependence were evaluated. They found the WHODAS 2.0 could be an appropriate substitute for the GAF. As a measure of disability, although the 12-item WHODAS 2.0 was not a particular instrument for mental health, it was sensitive to the effects of and the changes in mental disorders. The clinical implementation of this measure, they cautioned, needed further assessment.

Carlozzi et al. (2015) tested the reliability and design validity of the 12-item WHODAS-2.0 in individuals with Huntington's disease. They concluded that findings support the reliability and validity of the WHODAS 2.0 in individuals with Huntington's disease.

Another research by Ustün et al. (2010), compared the WHODAS-12 with other measures of functional disability such as FIM (Functional Independent Measurement), LHS (London Handicap Scale), SF-12 and SF-36 (Short Form Health Surveys) and WHOQOL (WHO Quality of Life). They found that the WHODAS 2.0 12-item version had strong concurrent validity for the general population.

2.4 Studies using the WHODAS 2.0. 12 Item Version

The main purpose of the Weeks et al., (2016) research was to include a comprehensive description of mental disorders and disability within the Canadian Armed Forces (CAF). The findings suggest that in this population, the WHODAS-2 is a good indicator of the disability. As hypothesised, CAF members with recent

mental disorders had a greater disability than those who have no life-long disorder, and disability increased with the number of new mental disorders. The results showed no (59%), mild (30.8%), moderate (8.4%), and severe (1.6%) disability. When compared with male participants, female participants had substantially higher scores for impairment. For rising age groups, the disability ratings were substantially higher. While specific disorders were relatively comparable in terms of the proportion of categories of disability, Alcohol Use Disorder was associated with a lower disability relative to other conditions. Remote disorders have been associated with a much smaller increase in disability compared to recent disorders. Persons with any new disorder, however, had different levels of disability with no (24.7%), mild (42.1%), moderate (26.0%), and severe (7.4%) disability. The extent of disability recorded varied as a function of the status of socio-demographic and military variables such as age, sex, service, rank and deployment.

The study by Tarvonen-Schröder et al. (2018) aims to explain the usefulness of the WHODAS 2.0 as a method for evaluating the effects of Traumatic Brain Injury (TBI). In this study, when comparing the functioning of patients with mild, moderate, and extreme TBI, the average degree of disability in the ability to function and operate had a tendency to increase with increased severity of TBI. The WHODAS 2.0 sum score (severe impairment in each group) or the workability score did not differ significantly between the patient groups even though the score tended to increase with increasing TBI severity. Significant differences between groups were found in standing, walking, washing, and dressing when comparing the 12 items separately. No differences between groups were found in household tasks, emotional functions, learning, concentrating, community life, dealing with strangers or maintaining friendships, where impairments were stated to be around moderate.

Such impairments were rated similarly to the patients by significant others. This study suggests that it is appropriate to determine disability using the 12-item WHODAS 2.0 and may be used in the designing of customer-oriented programs for TBI patients. In the chronic phase, patients with mild to severe TBI experience a variety of difficulties in activities and participation.

The aim of the study by Tarvonen-Schröder et al., (2019) was to compare the usefulness of 2 brief scales (WHODAS 2.0 and the minimal generic set by WHO) in assessing functioning in Spinal Cord Injury. When patients and their caregivers using the WHODAS 2.0 were rated for functioning, the overall disability score showed extreme impairment in all patient groups. Difficulties reported in cognition, participation, and relationships remained mild, with the exception of moderate impairment in community life in those with partial tetraplegia. All patient groups reported serious difficulties in standing, walking, and working ability, with the most severe restrictions in those with tetraplegia. When comparing tetraplegic and paraplegic groups, similar differences between groups were also found in household and self-care activities. When comparing the scores of those with a complete lesion with those with a partial lesion, a complete lesion was associated with more difficulty getting around and self-care, and a partial lesion with difficulty involving participation. Of these two tools, authors suggest using the 12-item patient-completed WHODAS 2.0, since this can be used with little effort to identify limitations of activity and limits of participation in SCI and distinguish between various severities and rates of SCI while preparing recovery services.

Another study by Tarvonen-Schröder, Hurme, et al. (2019) compared the shortest generic functioning measures based on ICF (the WHODAS 2.0 12-item and WHO Minimal Generic Set of Functional and Health Domains) with largely used

dependency and stroke severity measures. The results support both generic measures' usefulness in subacute stroke rehabilitants. The degree of impairment has been found to increase from mild to severe stroke. Both short measures have been strongly linked to conventional stroke severity and dependency measures. Patient and proxy WHODAS scores also mostly correlate well with each other, better in activities such as mobility, household tasks and self-care than in participation, relationships and cognition. Working capacity has been scored more affected in severe stroke according to significant others and a physician than the patients themselves. The rehabilitants with a WHODAS patient response were categorised into mild, moderate, and severe stroke while comparing background data in various severity groups of stroke. Differences between groups were found in all other items, with increasing impairment from mild to severe stroke, except for concentration. The most severely scored item was working ability, which in all groups was severe to very severely impaired; the only other items rated as severely impaired were mobility and household tasks in the "severe stroke" group. Both significant others and a neurologist rated non-respondent patients as having severe difficulties in all the functions measured expect moderate emotional and concentrative difficulties.

Waterhouse et al. (2017) used the WHODAS 2.0 to examine the relationship between multi-morbidity and disability in South African older adults. This research presented a new knowledge about the impact of hypertension and socio-demographic characteristics on this relationship within the region. Individuals with severe disability were substantially more likely to be older, of Indian or Asian ethnicity, divorced, separated or widowed, have low educational rates, belong to the quintile of poor or high wealth, reside in rural areas. The majority (61.4 percent) of the sample reported no chronic diseases, while 25.4% had one and 13.2% two or more chronic

diseases. Results indicated that with the number of chronic diseases increases, the proportion of people with severe disability rises. Similarly, the percentage of disability was observed to be progressively higher with an increase in the number of chronic conditions. When the interactions between the number of chronic conditions and sex, ethnicity, and wealth were analysed, only the interaction between wealth and the number of chronic diseases was found significant and consistent.

To sum up, the WHODAS 2.0 tackles the need and provides a consistent measure of health and disability. The WHODAS 2.0 is a popular and highly reliable self-report questionnaire designed to measure disability. It is important to find how individuals with aphonia secondary to total laryngectomy perform in this measure of functional ability.

Chapter 3

Method

3.1. Participants

The current investigation comprised of 23 participants between the ages of 18 to 70 years with the diagnosis of aphonia secondary to total laryngectomy. Out of 23, 19 participants met the inclusionary criteria and were included in the study.

3.1.1 Participant selection Criteria

Among the 23 participants, 19 were asked to provide written consent before the procedure, and four were excluded from the sample as they did not fulfil the inclusion criteria. All the participants were selected from different regions of Karnataka, who understand and speak Kannada or English. The diagnosis of aphonia secondary to total laryngectomy was confirmed during the preliminary interaction. Patients who had undergone surgery not less than three months ago were included. Those participants who had any history of intellectual disability/ borderline intelligence with or without visual/ hearing/ locomotor disability, psychiatric or degenerative neurological conditions, cardiovascular or respiratory disorders and diabetes mellitus were excluded from the study. Participants with any other residual or recurrent tumours were also excluded from the study.

3.2. Measures/ Materials

Tools mentioned below were used in the research study:

1. Socio Demographic Data

This data provided the details on participants' names, age, gender, date of birth, date of surgery, address, contact numbers, socio-economic status, education,

family details etc. Variables such as occupation and income were taken from the Modified Kuppaswamy Socio-economic Status scale (Sharma, 2017).

2. RPWD Speech Disability Measures

I. Speech Intelligibility Test. The percentage of Speech Intelligibility Affected (SIA) was measured using the "Perceptual Rating Scale (SRMC, Chennai)".

II. Voice Test. For measuring percentage of "Overall Voice Clarity Affected (OVCA)", "Consensus Auditory Perceptual Evaluation of Voice (CAPE V)" was used which includes breathiness, roughness, pitch, strain and loudness. CAPE V is a tool developed for the clinical auditory-perceptual assessment of voice.

It describes the voice problem with respect to the severity of auditory-perceptual characteristics (ASHA CAPE-V Form, n.d.; Kempster et al., 2009)

III. Speech Disability Percentage =

$$\frac{(2 \times \text{Upper range of percentage of SIA}) + \text{Upper range of percentage of OVCA}}{3}$$

3

3. WHO Disability Assessment Schedule.

A practical, generic assessment tool that provides health and disability measures at various typical and disordered populations. The present study used a 12-item self-administered version of the WHODAS 2.0. It describes the level of functioning in six domains of life (Ustün et al., 2010).

- Domain 1- Cognition: understanding and communicating
- Domain 2- Mobility: moving and getting around

- Domain 3-Self-care: taking care of one's hygiene, dressing, eating and staying alone
- Domain 4- Getting along: interacting with other people
- Domain 5- Life activities: domestic responsibilities, leisure, work and school
- Domain 6- Participation: involving in community activities, participating in society.

This assessment tool does not explicitly focus on a disease, so it can be used to measure disability in various diseases. In the general population and many other disorders, the instrument's usage is already proven to evaluate the disability.

There are many versions of the WHODAS 2.0. There are 36 questions in the full version, and there are 12 questions in the shorter version. These questions assess the difficulties experienced by a person in their life in the past 30 days in six domains of the tool. Recall abilities are most effective for one month. Hence, the past 30 days were chosen as the timeframe for the WHODAS 2.0. The 12 item questionnaire describes almost 81% of the variance of the full 36-item version. The 12-item version of the WHODAS 2.0 has a similar structure to the WHODAS-36 and consists of two questions for each domain, one with a low level of complexity and the other with a high level of functionality (domain) being evaluated (Ustün et al., 2010; World Health Organization, 2001). In the 12 item WHODAS 2.0, questions are labelled from S1 to S12. These comprise two corresponding questions from each of the six domains. Item S3 and S6 belong to domain 1, S1 and S7 to

domain 2, S8 and S9 to domain 3, S10 and S11 to domain 4, S2 and S12 to domain 5 and item S4 and S5 belongs to domain 6.

The sound theoretical underpinnings, various applications in different groups, excellent psychometric properties, and settings, and ease of use makes the WHODAS 2.0 particularly useful (Üstün, 2010). We used four categories of severity following the ICF (no disability, 0 to 4; mild disability, 5 to 24; moderate disability, 25 to 49; and severe/extreme disability, 50 to 100) (World Health Organization, 2001).

Scoring the WHODAS 2.0. The 12-item WHODAS 2.0 contains 12 Likert-style scale questions with possible answers ranging from "none" to a "extreme" amount of difficulty over the past 30 days with an area of function. While the WHODAS 2.0 responses can be algorithmically calculated using IRT weighting. The present study used results obtained using the "simple scoring" method for calculating the WHODAS scores (Ustün et al., 2010). The WHODAS manual explains that simple scoring is adequate because of the one-dimensional structure and high internal consistency of the scale, to "describe the degree of functional limitations" (Ustün et al., 2010). Simple scores are obtained by summing the values attributed to each response, in which *none* = 0, *mild* = 1, *moderate* = 2, *severe* = 3 and *extreme* = 4. Possible WHODAS 2.0 12-item scores range from 0 to 48; a score of 0 indicates that the endorsement was "none" for all items. Individuals missing one or more than one WHODAS response were not included in the analysis.

3.3. Procedure

Informed written consent was obtained from all the participants. Based on the inclusion and exclusion criteria, 19 participants with aphonia secondary to total

laryngectomy were selected by the investigator from different hospitals and home visits. Face to face interview was carried out to collect the socio-demographic data of the participants.

The present study involved two stages. Stage 1 involved measuring the percentage of disability using the RPWD Speech Disability Measures. In stage 2, the WHODAS 2.0 was used to measure the percentage of disability. All the measures were administered in a single session.

3.3.1. Stage 1

The percentage of Speech Intelligibility Affected (SIA) was measured using the "Perceptual Rating Scale (SRMC, Chennai)". It is a seven-point rating scale, with a rating of 1 being intelligible and 7 being unintelligible. Then, the percentage of Overall Voice Clarity Affected (OVCA) was measured using the Consensus Auditory Perceptual Evaluation of Voice (CAPE V). Participants were initially asked to phonate sustained vowels. Two vowels were included for this task. One is considered a lax vowel (/a/) and the other tense (/i/). Participants were given a standard Kannada or English standard rainbow passage to readout. Then the examiner elicited at least 20 seconds of natural conversational speech using standard interview questions such as, "Tell me about your voice problem" or "Tell me how your voice is functioning?". These scores were used to calculate the percentage of disability using the formulae given by RPWD Speech Disability Measures.

3.3.2. Stage 2

Stage 2 of the study involved administering the WHODAS 2.0 12-item self-administered version. Instructions were provided before they start filling the questionnaire. Participants were asked to look back about the last 30 days and

answer the questions, thinking about how much trouble they had doing the listed activities. They had been asked to circle only one answer for every item.

3.4. Statistical Analysis

The tabulated data were analysed using SPSS for Windows version 21.0. Descriptive analysis was done on the collected data using mean and standard deviation. Frequency distribution was obtained for socio-demographic and clinical characteristics. Bivariate analysis was done between the scores of the WHODAS 2.0 and socio-demographic and treatment-related clinical variables using Spearman's (rho) correlation coefficient.

Chapter 4

Results

Twenty-three individuals with aphonia secondary to total laryngectomy were interviewed for the study. Of the 23 individuals, four were excluded as they had another existing disorder (three participants with a self-reported diagnosis of diabetes mellitus and another participant with a history of seizure disorder). The remaining 19 participants, who met the inclusion criteria and provided the written consent, were included in the study. Table 1 and 2 show the socio-demographic and clinical characteristics of the participants ($N= 19$). The mean age of the patients was 59.84 years, and 94.7% of them being male.

Table 1*Socio-demographic Characteristics of Participants*

Socio-demographic Variables		Total ($N = 19$)	
		<i>n</i>	%
Age (Years), <i>M (SD)</i>		59.84	10.17
Gender	Male	18	94.7
	Female	1	5.3
Family type	Joint	8	42.1
	Nuclear	11	57.9
Family size, <i>M (SD)</i>	Adult	4.37 (1.30)	
	Children	1.42 (1.26)	
Marital status	Unmarried	-	-
	Married	19	100
	Separated	-	-
	Divorced	-	-
	Widowed	-	-
Years of education, <i>M (SD)</i>		9.37 (3.93)	

Employment status	Unemployed	2	10.5
	Unskilled worker	6	31.6
	Semi-skilled worker	-	-
	Skilled worker	1	5.3
	Clerical or Shop or Farm	5	26.3
	Semi-professional	3	15.8
	Professional	2	10.5
	Monthly percapita income	Less than 100	-
	101 – 299	-	-
	300 – 499	-	-
	500 – 749	-	-
	750 – 999	3	15.8
	1000 – 1999	6	31.6
	Rs. 2000 and above	10	52.6

Note. Empty cells are marked using “-” which means that no data were reported.

TABLE 2

Treatment-related clinical characteristics of participants

Clinical Variables	<i>M</i>	<i>SD</i>
Years since diagnosis	6.84 (6.31)	6.31
Years since surgery	5.58 (5.88)	5.88
Length of hospital stay post-surgery (Days)	18.58 (7.99)	7.99

The severity of disability scores and the pattern of disability scores are presented in Tables 3 - 6. The mean WHODAS 2.0 total score was 12.95 ($SD = 7.61$), and the summary score was 26.97 ($SD = 15.85$). Out of the whole sample, almost all (94 %) experienced some level of disability; mild (47.36 %), moderate (26.31 %), and severe (21.05 %). Only one of the participants (5.26%) reported no disability.

In the 12 item WHODAS 2.0, the 90th percentile- a cut-off score for severe disability- had a summary score of 17 and above. This is similar to the ICF's Disability Levels, which define severe disability as a score on a standardised instrument for self-reported activity/participation over 50% (WHODAS 2.0 score 50) and up to 95% of the score range (World Health Organization, 2001). Table 3 shows the mean disability percentile score of the population sample as 91.44 ($SD = 8.83$). It is notable that the mean disability percentage calculated according to RPWD Act measures was 100 ($SD = 0$). The percentage of individuals who scored above the 90th percentile cut-off for severe disability was 73.68% (Table 4).

Table 5 describes the pattern of disability by each ICF category. Item S5, "emotionally affected", was the most affected category ($M = 2.47$, $SD = 1.34$) and item S3, regarding "learning", was the least affected ($M = 0.16$, $SD = 0.5$). Table 6 describes the pattern of disability by each WHODAS 2.0 domain score. While, with a mean score of 3.53 ($SD = 1.61$), the "participation: involving in community activities" domain was the most affected, the "cognition: understanding and communicating" domain was the least affected ($M = 0.84$, $SD = 1.38$).

Table 3

Percentage of disability by RPWD Measures and the WHODAS 2.0 in participants

Severity of Disability ($N = 19$)			
Percentage of Disability (RPWD Act) $M (SD)$	WHODAS 2.0		
	Total Score $M (SD)$	Summary Score $M (SD)$	Population Percentile $M (SD)$
100 (0)	12.95 (7.61)	26.97 (15.85)	91.44 (8.83)

Table 4*Severity of disability by the WHODAS 2.0 in participants*

Severity of disability, Total (N = 19)				
<i>n (%)</i>				
None	Mild	Moderate	Severe / Extreme	% of persons with severe disability (score > 90 th percentile)
1 (5.26)	9 (47.36)	5 (26.31)	4 (21.05)	14 (73.68)

Table 5*Pattern of disability by each ICF categories in participants*

ICF categories	M	SD
S1 – Standing	0.79	0.85
S2 – Household	0.74	0.93
S3 – Learning	0.16	0.50
S4 – Joining community	1.10	1.07
S5 – Emotionally affected	2.47	1.34
S6 – Concentrating	0.68	1.10
S7 – Walking	1.47	1.17
S8 – Washing	1.16	1.06
S9 – Dressing	0.53	1.12
S10 – Dealing do not know	1.32	1.25
S11 – Maintaining friendship	1.58	1.46
S12 – Work	1.00	1.33

Table 6*Pattern of disability by the WHODAS 2.0 domain in participants*

Domains	M	SD
Cognition	0.84	1.38
Getting around	2.26	1.79

Self-care	1.68	2.08
Getting-along	2.89	1.94
Life activities	1.74	1.93
Participation	3.53	1.61

The current study also aimed to analyse the association of the socio-demographic and treatment-related clinical variables on the scores of disability in participants with aphonia secondary to total laryngectomy. The correlation coefficient between the age of the participants and domain 6 (Participation: involving in community activities) was low negative ($r_s = -0.46$). On the other hand, the size (adult) of the family and "cognition" domain has shown a moderate positive correlation ($r_s = 0.502$). Similarly, a positive correlation was seen between the family size (children) and domain 1 (Cognition) and 2 (Getting around). The monthly per capita income of the participants was the only socio-demographic variable that had an association with the total score. The monthly per capita income showed a significant high negative correlation with the total score ($r_s = -0.72$, $p = 0.00$) and significant moderate negative correlation with domain scores 4 (Getting along) and 5 (Life activities).

The correlation between the clinical variables with the WHODAS 2.0 scores (Table 8) indicated no correlation between them.

Table 7

Spearman correlation of sociodemographic variables with the WHODAS 2.0 domain

Socio-demographic variables	WHODA S 2.0 total score	D1	D2	D3	D4	D5	D6
Age (Years) r_s	-.02	.43	.36	-.38	-.09	-.24	-.46*

	<i>p</i>	.917	.066	.129	.105	.693	.318	.046
Family size (Adult)	<i>r_s</i>	.43	.50*	.38	.25	.04	.40	-.05
	<i>p</i>	.064	.028	.101	.287	.871	.086	.829
Family size (Children)	<i>r_s</i>	.35	.62**	.47*	.13	.17	.29	-.09
	<i>p</i>	.139	.004	.040	.573	.478	.224	.692
Years of education	<i>r_s</i>	-.15	-.00	.13	-.05	-.06	-.23	-.08
	<i>p</i>	.537	.997	.587	.817	.799	.323	.731
Employment status	<i>r_s</i>	-.29	-.14	.00	-.07	-.41	-.028	-.17
	<i>p</i>	.219	.566	.991	.772	.078	.242	.477
Monthly per capita income	<i>r_s</i>	-.72**	-.43	-.43	-.34	-.68**	-.62**	-.45
	<i>p</i>	.000	.065	.064	.150	.001	.004	.052

Note. D = Domain

* $p < .05$. ** $p < .01$

Table 8

Spearman correlation of treatment related clinical variables with the WHODAS 2.0 domain

Clinical variables		D1	D2	D3	D4	D5	D6
Years since diagnosis	<i>r_s</i>	.01	-.08	-.34	.09	-.20	.05
	<i>p</i>	.958	.728	.149	.697	.404	.814
Year since surgery	<i>r_s</i>	-.06	-.26	-.27	.15	-.18	.04
	<i>p</i>	.806	.276	.261	.522	.449	.848
Length of hospital stay post-surgery	<i>r_s</i>	.11	-.20	-.10	.06	-.21	-.21
	<i>p</i>	.644	.395	.661	.786	.374	.384

Note. D = Domain

Chapter 5

Discussion

Self-reported measures are widely used to assess the outcome of treatment and to design suitable intervention strategies for the management of chronic conditions (Cudkowicz et al., 2004). The purpose of the present study was to determine the extent of disability in persons with aphonia secondary to total laryngectomy using a self-reported measure: - the 12-item WHODAS 2.0. The current study employed (a) measures as recommended by the RPWD Act Guidelines 2018 and (b) the WHODAS 2.0 to assess and identify the extent of disability in persons with aphonia secondary to total laryngectomy. In addition, the influence of socio-demographic and treatment-related clinical variables on disability scores was also examined. To my knowledge, this is the first study to have carried out an analysis of the 12-item WHODAS 2.0 in Total Laryngectomy population.

All but one of the participants in the study sample were male, and the mean age of the sample was 59 years. Typically, a large proportion of patients who undergo laryngectomy are older adult males. A study by Deshpande et al. in 2009 had 68% of participants over 50 years of age, and 97% of them were males. Another study by Trivedi et al. in 2008 has a mean age of 60 years for participants with total laryngectomy, and the percentage of male participants were 72%. Another noticeable characteristic of the study-sample was that all the participants were married and living with their spouse.

Percentage of disability under the RPWD Act Guidelines 2018 for persons with total laryngectomy was found to be a constant 100% for all participants in this study. The stepwise guideline for the assessment of speech disability in the RPWD Act includes the use of the Perceptual Rating Scale (SRMC, Chennai) for the

calculation of the percentage of Speech Intelligibility Affected (SIA) and the Consensus Auditory Perceptual Voice Evaluation (CAPE V) for the measurement of the percentage of Overall Voice Clarity Affected (OVCA). The SIA ratings of all the participants were "unintelligible", and the OVCA ratings were "extremely deviant" due to severe unintelligible breathy voice output. Therefore, the disability percent calculated according to the RPWD Act Guidelines was 100% for all the participants. In contrast, the WHODAS 2.0 mean disability population percentile score of the sample was 91.44 (SD =8.83). It is also notable that 73% of the individuals scored above the 90th percentile cut-off for severe disability. The WHODAS 2.0 results suggest that disability is not merely a health issue. It is a complex phenomenon, reflecting the interaction between a person's body characteristics and the characteristics of a society in which he or she lives (John et al., 2018). Therefore, rating 100% disability based on symptom severity is an oversimplification.

Another result from the present analysis showed that the mean and SD of the WHODAS 2.0 total score was 12.95 (7.61). According to a study, which surveyed more than 65,000 respondents, the general population has mean less than 10 for each domain and overall scores (Ustün et al., 2010). Our finding was also consistent with that of the Abedzadeh-Kalahroudi et al. (2015) study that showed the patients with trauma (single or multiple organs) also had a similar WHODAS 2.0 overall score. A different study by Lee et al. (2017) examined how cancer and treatment sequelae combined with comorbidities to influence restrictions on physical functioning and participation in activity. With regard to functional status, their data showed that cancer-related factors played a role in functional limitations and had a modest indirect impact on participants' perceptions of their functioning.

Age of the participant had a significant negative correlation with functional problems, particularly with regard to the restriction of social participation. The picture that emerges from the current data is that the restriction of participation due to laryngectomy is more distressing for younger adults than for older adults. This finding is consistent with that of the Williamson & Schulz, (1995), in which they found that the restriction of daily activities due to pain and illness could be more distressing for individuals under the age of 65 years than those 65 years of age or older. Older people think about health and disability in various ways, contrasting their own health status with that of other older people or with common cultural assumptions about deteriorating health in old age. The current study finding reflects a pattern in which older adults, with a higher number of medical disorders, become more accustomed to lower levels of functional ability when considering these changes as a natural part of their ageing. It is possible that this adjustment can occur at any age. However, a transition may be more difficult for those who have not yet reached an age when the functional limitation is normal or expected. Adding credence to this finding is another finding of the current study that showed none of the WHODAS 2.0 scores correlated with years since diagnosis or years since surgery. It is obvious that the age, not years, of suffering matters.

With reference to the pattern of disability, persons with aphonia secondary to total laryngectomy felt participation in community activities as the most affected and cognition as the least affected domain. When each of the 12 ICF categories were compared, the item regarding emotional consequences was the most affected, and the item regarding learning was the least affected. Stigma and discrimination are powerful forces in society that have a profound impact on the lives of people affected by stigmatised health conditions, like laryngeal cancer, where a physical

appearance of the stoma is visible. Thus, persons with aphonia secondary to total laryngectomy may harbour feelings of shame and embarrassment, limiting their community involvement. In addition, talking to, and having a conversation with, others is one of the essential activities in social participation. Individuals with aphonia secondary to total laryngectomy may experience communication breakdowns with others. Reduced smoothness of communication during interactions can lead to reduced satisfaction with social participation. Similar findings were recently reported by Lee et al. (2017). In their study on individuals with colorectal cancer, a similar pattern of disability ("participation" domain being the most, and "cognition" being the least affected) was found. Another study by James & Mukundan (2017) found that in individuals with tinnitus "participation" domain was the most affected and "self-care" domain was least affected. In contrast to the current study, Chang et al. (2018), while comparing individual with visual impairment (VI) and hearing impairment (HI), found that the domain "household activities" was the most affected for VI group and "getting along" was the most affected in HI group. The "self-care" domain was the least affected for both the groups.

Another interesting generalised trend revealed in the study is that the functional deficits experienced in the "cognition" domain increased when the number of members in the family increased. A possible explanation is that a person living on his or her own may be actively involved in mental, social and financial activities, requiring appropriate thought, preparation, decision-making and executive action. Involvement in these activities can result in stimulating brain activity and neuron growth, lowering the risk of cognitive decline. Thus, the cognitive performance of the elderly living alone is more likely to be higher than those living

with more people. Gleib et al. (2005) also reported that voluntary social experiences might have a greater effect than family or inmate relationships on cognitive function.

Out of all the socio-demographic and treatment-related clinical variables analysed, monthly per capita income was the only one variable that had a correlation with the WHODAS 2.0 total score. A very high negative correlation existed between them. The poorer the individual, the more severe the disability. This association is too well known to be reiterated. Suffice to say, this association is reflected in the clinical group of persons with aphonia secondary to total laryngectomy as well. Most often, the poorest are unable to access services that enable them to adapt to disorders.

In interpreting the results of the present research, there are a few limitations. First, the study sample accrued from a limited group of academic centres. Second, the sample was restricted to a specific subgroup of laryngectomy (i.e., Total Laryngectomy) leaving out other subgroups of laryngectomy. Third, purposive, not random, sampling was employed to recruit the patients. Fourth, the sample size was small. Finally, the role of gender was not studied since the sample included only one female participant.

Future research can employ a more adequate and more representative sample. It is also possible to assess functional changes before and after treatment to determine how functioning before cancer treatment influenced post-treatment functioning. Additional prospective studies are needed to gain a better understanding of the continuing changes in the functional ability of persons with aphonia secondary to total laryngectomy.

Chapter 6

Summary and Conclusion

The present study was conducted to determine the extent of disability in persons with aphonia secondary to total laryngectomy. Understanding what kind of disease a patient has helps in formulating intervention strategies and predicting outcomes. However, diagnosing a condition is not enough to fully understand the patient and his or her life experience. An important aspect is one's life activities and works necessary to fulfil one's role in different social spheres. The World Health Organization has developed a "WHO Disability Assessment Schedule" (WHODAS 2.0) to address this need and to provide a standardised measure for health and disability across cultures. The 12-item version of WHODAS 2.0 takes only 5 minutes to be administered and has been used in many population-level surveys to obtain scores for six domains (Cognition, Mobility, Self-care, Getting along, Life-Activities and Participation) of functioning. The current research used (a) measures as suggested by the 2018 RPWD Act Guidelines and (b) the WHODAS 2.0 to determine and identify the severity of the disability in persons with aphonia secondary to total laryngectomy. In addition, the influences of various socio-demographic and treatment-related clinical variables on disability scores were also investigated. The data thus obtained were subject to quantitative analysis. Spearman's (rho) correlation was used to correlate the data.

There were 19 individuals (18 males and one female) with aphonia secondary to total laryngectomy in the study. The first stage of the study included measuring the disability percentage using the RPWD Act Guidelines 2018. The second stage of the study included administering the WHODAS 2.0 self-administered 12-item version.

The findings of the study revealed that the percentage of disability under the RPWD Act Guidelines 2018 for persons with total laryngectomy was a constant 100% for all participants. On the other hand, the mean disability population score of the WHODAS 2.0 was 91.44 (SD=8.83). It is also noteworthy that 73% of individuals scored above the 90th percentile cut-off for severe disability.

Age of the participant had a significant negative correlation with functional problems, particularly with regard to the restriction of social participation. With reference to the pattern of disability, persons with aphonia secondary to total laryngectomy felt participation in community activities as the most affected and cognition as the least affected domain. When each of the 12 ICF categories were compared, the item regarding emotional consequences was the most affected, and the item regarding learning was the least affected. Out of all the socio-demographic and treatment-related clinical variables analysed, monthly per capita income was the only one variable that had a correlation with the WHODAS 2.0 total score. A very high negative correlation existed between them.

The WHODAS 2.0 results suggest that disability is not merely a health issue. It is a complex phenomenon, reflecting the interaction between the characteristics of a person's body and the characteristics of a society in which he or she lives.

6.1. Clinical Implications

There are several clinically significant implications of the study findings. The first contribution of the present study is that it provides empirical data to highlight the issue that is rating the severity of any disease and the functional disabilities due to that disease are two distinct and different activities.

Second, the 12-item version of WHODAS 2.0 takes just 5 minutes to administer and can be used to assess the functional disabilities in person with aphonia secondary to total laryngectomy. It can be easily incorporated in the standard clinical practice.

Third, Persons with total laryngectomy may find the loss of normal speech as its most serious consequence. The current study findings suggested that they felt a decline in community participation and emotional health. There is a need for targeted intervention to improve functioning in these areas.

References

- American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders (DSM-5®)*. American Psychiatric Pub.
- ASHA CAPE-V Form. (n.d.). American Speech-Language-Hearing Association. Retrieved August 19, 2019, from <https://www.asha.org/Form/CAPE-V/>
- Baselga, J. (2002). Why the epidermal growth factor receptor? The rationale for cancer therapy. *Oncologist*, 2–8.
- Cann, R. K. (1980). C1, Flanders D, Fladers D, Fried MP. Epi-demiology of laryngeal cancer. *Epidemiol Rev*, 2, 195–209.
- Carlozzi, N. E., Kratz, A. L., Downing, N. R., Goodnight, S., Miner, J. A., Migliore, N., & Paulsen, J. S. (2015). Validity of the 12-item World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) in individuals with Huntington disease (HD). *Quality of Life Research*, 24(8), 1963–1971. <https://doi.org/10.1007/s11136-015-0930-x>
- Chang, K.-F., Chang, K.-H., Chi, W.-C., Huang, S.-W., Yen, C.-F., Liao, H.-F., Liou, T.-H., Chao, P.-Z., & Lin, I.-C. (2018). Influence of visual impairment and hearing impairment on functional dependence status among people in Taiwan—An evaluation using the WHODAS 2.0 score. *Journal of the Chinese Medical Association*, 81(4), 376–382. <https://doi.org/10.1016/j.jcma.2017.08.011>
- Chaturvedi, P., Pawar, P. V., Syed, S., Nair, D., Dutta, S., Chaukar, D., & D’Cruz, A. K. (2013). A clinical survey of laryngectomy patients to detect presence of the false perception of an intact larynx or the “phantom larynx” phenomenon. *Indian Journal of Medical and Paediatric Oncology : Official Journal of*

Indian Society of Medical & Paediatric Oncology, 34(1), 3–7.

<https://doi.org/10.4103/0971-5851.113394>

Deacon, B. J. (2013). The biomedical model of mental disorder: A critical analysis of its validity, utility, and effects on psychotherapy research. *Clinical Psychology Review*, 33(7), 846–861.

<https://doi.org/10.1016/j.cpr.2012.09.007>

Engel 1980 *The clinical application of of the biopsychosocial model.pdf*. (n.d.).

Retrieved June 26, 2020, from

<https://www.acesconnection.com/fileSendAction/fcType/0/fcOid/466307103267301137/filePointer/466166364394606238/fodoid/466166364394606234/Engel%201980%20The%20clinical%20application%20of%20of%20the%20biopsychosocial%20model.pdf>

Forastiere, A. A., Ang, K. K., Brizel, D., Brockstein, B. E., Burtness, B. A., Cmelak, A. J., Colevas, A. D., Dunphy, F., Eisele, D. W., Goepfert, H., Hicks, W. L., Kies, M. S., Lydiatt, W. M., Maghami, E., Martins, R., McCaffrey, T., Mittal, B. B., Pfister, D. G., Pinto, H. A., ... Worden, F. (2008). Head and neck cancers. *JNCCN Journal of the National Comprehensive Cancer Network*, 6(7), 646–695.

Habtamu, K., Alem, A., Medhin, G., Fekadu, A., Dewey, M., Prince, M., & Hanlon, C. (2017). Validation of the World Health Organization Disability Assessment Schedule in people with severe mental disorders in rural Ethiopia. *Health and Quality of Life Outcomes*, 15(1), 64.

<https://doi.org/10.1186/s12955-017-0647-3>

- Hall, R. C. W. (1995). Global Assessment of Functioning: A Modified Scale. *Psychosomatics*, 36(3), 267–275. [https://doi.org/10.1016/S0033-3182\(95\)71666-8](https://doi.org/10.1016/S0033-3182(95)71666-8)
- James, M. M., & Mukundan, D. G. (2017). *Use of WHODAS 2.0 in Tinnitus Patients: Correlating Results with THI*.
- Jemal, A., Siegel, R., Ward, E., Murray, T., Xu, J., & Thun, M. J. (2007). Cancer Statistics, 2007. *CA: A Cancer Journal for Clinicians*, 57(1), 43–66. <https://doi.org/10.3322/canjclin.57.1.43>
- John, T., Subramanyam, A. A., & Sagar, R. (2018). Strength and weakness of the guidelines of Rights of Persons with Disabilities Act, 2016 (dated January 5, 2018): With respect to the persons with neurodevelopmental disorders. *Indian Journal of Psychiatry*, 60(3), 261–264. https://doi.org/10.4103/psychiatry.IndianJPsychiatry_326_18
- Kempster, G. B., Gerratt, B. R., Verdolini Abbott, K., Barkmeier-Kraemer, J., & Hillman, R. E. (2009). Consensus auditory-perceptual evaluation of voice: Development of a standardized clinical protocol. *American Journal of Speech-Language Pathology*, 18(2), 124–132. [https://doi.org/10.1044/1058-0360\(2008/08-0017\)](https://doi.org/10.1044/1058-0360(2008/08-0017))
- Lilienfeld, S. O. (2007). Cognitive neuroscience and depression: Legitimate versus illegitimate reductionism and five challenges. *Cognitive Therapy and Research*, 31(2), 263–272. <https://doi.org/10.1007/s10608-007-9127-0>
- Manni, J. J., Terhaard, C. H. J., de Boer, M. F., Croll, G. A., Hilgers, F. J. M., Annyas, A. A., van der Meij, A. G. L., & Hordijk, G. J. (1992). Prognostic factors for survival in patients with T3 laryngeal carcinoma. *The American*

Journal of Surgery, 164(6), 682–687. [https://doi.org/10.1016/S0002-9610\(05\)80734-2](https://doi.org/10.1016/S0002-9610(05)80734-2)

Nawka, T., & Hosemann, W. (2005). Surgical procedures for voice restoration. *GMS Current Topics in Otorhinolaryngology, Head and Neck Surgery*, 4. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3201008/>

Sharma, R. (2017). Revised Kuppuswamy's socioeconomic status scale: Explained and updated. *Indian Pediatrics*, 54(10), 867–870. <https://doi.org/10.1007/s13312-017-1151-x>

Sjonnesen, K., Bulloch, A. G. M., Williams, J., Lavorato, D., & B. Patten, S. (2016). Characterization of Disability in Canadians with Mental Disorders Using an Abbreviated Version of a DSM-5 Emerging Measure: The 12-Item WHO Disability Assessment Schedule (WHODAS) 2.0. *Canadian Journal of Psychiatry. Revue Canadienne de Psychiatrie*, 61(4), 227–235. <https://doi.org/10.1177/0706743716632514>

Stell, P. M., & McGill, T. (1973). ASBESTOS AND LARYNGEAL CARCINOMA. *The Lancet*, 302(7826), 416–417. [https://doi.org/10.1016/S0140-6736\(73\)92275-7](https://doi.org/10.1016/S0140-6736(73)92275-7)

Tarvonen-Schröder, S., Hurme, S., & Laimi, K. (2019). The World Health Organization Disability Assessment Schedule (whodas 2.0) and the Who Minimal Generic Set of Domains of Functioning and Health Versus Conventional Instruments in Subacute Stroke. *Journal of Rehabilitation Medicine*, 51(9), 675–682. <https://doi.org/10.2340/16501977-2583>

Tarvonen-Schröder, S., Kaljonen, A., & Laimi, K. (2019). Utility of the World Health Organization Disability Assessment Schedule and the World Health Organization Minimal Generic Set of Domains of Functioning and Health in

Spinal Cord Injury. *Journal of Rehabilitation Medicine*, 51(1), 40–46.

<https://doi.org/10.2340/16501977-2501>

Tarvonen-Schröder, S., Tenovuoto, O., Kaljonen, A., & Laimi, K. (2018). Usability of World Health Organization Disability Assessment Schedule in Chronic Traumatic Brain Injury. *Journal of Rehabilitation Medicine*, 50(6), 514–518.

<https://doi.org/10.2340/16501977-2345>

Turk, D. C. (2002). *A Diathesis-Stress Model of Chronic Pain and Disability following Traumatic Injury* [Anxiety and Related Factors in Chronic Pain]. Pain Research and Management; Hindawi.

<https://doi.org/10.1155/2002/252904>

Ustün, T. B., Chatterji, S., Kostanjsek, N., Rehm, J., Kennedy, C., Epping-Jordan, J., Saxena, S., von Korf, M., Pull, C., & WHO/NIH Joint Project. (2010).

Developing the World Health Organization Disability Assessment Schedule 2.0. *Bulletin of the World Health Organization*, 88(11), 815–823.

<https://doi.org/10.2471/BLT.09.067231>

Waterhouse, P., van der Wielen, N., Banda, P. C., & Channon, A. A. (2017). The impact of multi-morbidity on disability among older adults in South Africa: Do hypertension and socio-demographic characteristics matter? *International Journal for Equity in Health*, 16(1), 62. <https://doi.org/10.1186/s12939-017-0537-7>

Weeks, M., Garber, B. G., & Zamorski, M. A. (2016). Disability and Mental Disorders in the Canadian Armed Forces. *The Canadian Journal of Psychiatry*, 61(1_suppl), 56S-63S.

<https://doi.org/10.1177/0706743716628853>

World Health Organization (Ed.). (2001). *International classification of functioning, disability and health: ICF*. World Health Organization.

Appendix

Consensus Auditory-Perceptual Evaluation of Voice (CAPE-V):

Name: _____

Date: _____

The following parameters of voice quality will be rated upon completion of the following tasks:

1. Sustained vowels, /a/ and /i/ for 3-5 seconds duration each.
2. Sentence production
3. Spontaneous speech in response to: "Tell me about your voice problem." or "Tell me how your voice is functioning."

C = Consistent	I = Intermittent
MI = Mildly Deviant	MO = Moderately Deviant
SE = Severely Deviant	

SCORES

Overall Severity -----MI-----MO-----SE----- C I ___/100

Roughness -----MI-----MO-----SE----- C I ___/100

Breathiness -----MI-----MO-----SE----- C I ___/100

Strain -----MI-----MO-----SE----- C I ___/100

Pitch (Indicate the nature of the abnormality):

-----MI-----MO-----SE----- C I ___/100

Loudness (Indicate the nature of the abnormality):

-----MI-----MO-----SE----- C I ___/100

Comments about resonance:

Other (Provide description): _____

Additional Features (for example, diplophonia, fry, falsetto, asthenia, aphonia, pitch instability, tremor, wet/gurgly, or other relevant terms):

Overall Voice Clarity Affected (OVCA):

SCORE	PERCENTAGE OF OVERALL VOICE CLARITY AFFECTED (OVCA)
1	0 – 15
2	16 – 30
3	31 – 39
4	40 – 55
5	56 – 75
6	76 – 89
7	90 – 100

Speech Intelligibility Affected (SIA): Perceptual Rating Scale (SRMC, Chennai)

RATING	SCORE	PERCENTAGE OF SPEECH INTELLIGIBILITY AFFECTED (SIA)
Intelligible	1	0 – 15
Listener attention needed	2	16 – 30
Occasional repetition of words required	3	31 – 39
Repetitions/ rephrasing necessary	4	40 – 55
Isolated words understood	5	56 – 75
Occasionally understood by others	6	76 – 89
Unintelligible	7	90 – 100

WHODAS 2.0 SELF-ADMINISTERED 12 ITEM VERSION:

In the past 30 days, how much difficulty did you have in:						
1	Standing for long periods such as 30 minutes?	None	Mild	Moderate	Severe	Extreme or cannot do
2	Taking care of your household responsibilities?	None	Mild	Moderate	Severe	Extreme or cannot do
3	Learning a new task, for example, learning how to get to a new place?	None	Mild	Moderate	Severe	Extreme or cannot do
4	How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	None	Mild	Moderate	Severe	Extreme or cannot do
5	How much have you been emotionally affected by your health problems?	None	Mild	Moderate	Severe	Extreme or cannot do
6	Concentrating on doing something for ten minutes?	None	Mild	Moderate	Severe	Extreme or cannot do
7	Walking a long distance such as a kilometre [or equivalent]?	None	Mild	Moderate	Severe	Extreme or cannot do
8	Washing your whole body?	None	Mild	Moderate	Severe	Extreme or cannot do
9	Getting dressed	None	Mild	Moderate	Severe	Extreme or cannot do
10	Dealing with people you do not know?	None	Mild	Moderate	Severe	Extreme or cannot do
11	Maintaining a friendship?	None	Mild	Moderate	Severe	Extreme or cannot do
12	Your day-to-day work?	None	Mild	Moderate	Severe	Extreme or cannot do