VELOPHARYNGEAL INSUFFICIENCY ON QUALITY OF LIFE OF ADULTS WITH REPAIRED CLEFT PALATE IN KENYATTA NATIONAL HOSPITAL, NAIROBI CITY COUNTY, KENYA

BY

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DECLARATION

This thesis is my original work and has not been presented in any other university for an award of a degree nor for consideration of certification. The work has been conducted with strict adherence to anti-plagiarism regulations. Any information borrowed elsewhere has been duly referenced and properly cited in accordance with the current APA system and upholds academic integrity.

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DEDICATION

I devote this thesis to my dear husband Andrew N. Karani for his tireless support, guidance and encouragement, to my dear father Zaverio Bundi for his encouragement to push on and to my beautiful children Ryan and Mitchelle for their continued support and prayers.

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ABBREVIATIONS AND ACRONYMS

ASHA	:	American Speech and Hearing Association
CP	:	Cleft Palate
KNH	:	Kenyatta National Hospital
OFCs	:	Orofacial Clefts
SLP	:	Speech and Language Pathologist
VPD	:	Velopharyngeal Deficiency
VPI	:	Velopharyngeal Insufficiency
QOL	:	Quality of Life
WHO	:	World Health Organization

ABSTRACT

Cleft palate is one of the most prevalent birth defects that impacts on the quality of life of both children and adults around the world. It is estimated that 10%-20% of patients with cleft palate will present with Velopharyngeal Insufficiency (VPI) residual post palatal repair. This study evaluated the effects of VPI on the quality of life among adults with repaired cleft palate in order to: to establish the effect of VPI on social interaction, and functional ability; determine the level of accessibility/availability of speech therapy and counseling services; and to also determine the role of speech therapy on communication of these patients. The study was guided by the Self-Verification Theory. The study targeted adults, both males and females with repaired cleft palate at Kenyatta Hospital, Nairobi City County. The study adopted a case study research design. 22 adults with repaired cleft palate, 2 maxillofacial surgeons and 1 speech and language therapist were purposively sampled for the study. Stratified random sampling was used to avoid gender bias. The pilot study was carried out at Kijabe Hospital. The data was collected using questionnaires, and interviews. The data was analyzed with the use of Statistical Package for Social Sciences version 21 for quantitative data. Categorical data was summarized using frequency tables and proportions. The study found out that VPI had significantly negative effects on different aspects of life of adults with repaired cleft palate; there was lower level of social interaction and functional ability due to challenges with speech production and perception, and low level of accessibility of speech therapy and counseling services. The study recommends that Hospitals should consider adopting speech therapy as a significant healthcare delivery section that will emphasize on improving the wellbeing of patients who need speech therapy and multidisciplinary team, i.e., maxillofacial surgeons, plastic surgeons, orthodontists, in understanding the quality of life for patients undergoing treatment at the facility, hence creation of better protocols in management of these patients.

CHAPTER ONE

INTRODUCTION AND BACKGROUND TO THE STUDY

1.1 Introduction

This chapter offers background information to the study and presents a statement of the problem alongside the purpose of the study, and research objectives, research questions, and significance of the study. The chapter also contains the limitation and delimitation of the study, assumptions of the study, theoretical framework, conceptual framework and closes with the operational definition of the terms used in the study.

1.2 Background to the Study

A separation of the anatomical parts of the mouth has been defined as a cleft. According to Kummer (2013), cleft palate refers to an opening in the roof of the mouth (hard and soft) such that the two sides making up the palate fail to join as the baby develops in the uterus (Kummer, 2013). During speech production, the soft palate gets elevated and touches the back of the throat thereby closing off the oral from the nasal cavity enabling sound from the mouth to come out as opposed from the nose. In production of nasal sounds, the soft palate stays down so that sound can travel out of the nose (Sitzman, 2014). Partial closure of the velopharynx during speech results to velopharyngeal insufficiency, a disorder that comes as a result of inadequate closing of the soft palate onto the pharyngeal wall during speech (Shprintzen, 2009).

There is structural alteration of the soft palate as well as the pharyngeal walls where there is not enough tissue for a complete closure of the pharyngeal sphincter during production of oral sounds. This disorder allows air to escape from the nose during speech resulting to

hyper nasal speech that is unintelligible (Wong et al., 2019). VPI is mostly caused by history of repaired or unrepaired cleft palate. The percentage of patients with residual VPI following cleft palate repair varies from Centre to Centre but in general it is estimated that 10%-20% of patients with cleft palate will present with VPI residual post palatal repair (Bhuskute, 2017).

Quality of Life (QOL) refers to "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (World Health Organization, [WHO] QQL, 1994). Quality of life seeks to obtain patients total health related experience by evaluating broad domains such as emotional, physical, functional, and spiritual wellbeing. The prevalence of Orofacial clefts is dependent on geographic origin, race, ethnicity and socioeconomic background which may vary from 1/500 to 1/2500 births, and it has been noted that Asians have the highest risk (14/10,000 births), which is followed by whites (10/10,000 births) and the African Americans (4/10,000 births) (D'Antonio & Nagarajan, 2003).

In a study conducted investigating the birth prevalence of orofacial clefts globally, it was revealed that in a study of 30,665,615 live births there were 45,193 patients with OFCs. Thus, based on continental distribution, the OFCs birth prevalence (95% confidence interval) from Asia, North America, Europe, Oceania, South America, and Africa were 1.57 (1.54-1.60), 1.56 (1.53-1.59), 1.55 (1.52-1.58), 1.33 (1.30-1.36), 0.99 (0.96-1.02), and 0.57 (0.54-0.60) per 1,000 live births, respectively. The American Indians had the highest prevalence rates of 2.62 per 1,000 live births, followed by the Japanese, the Chinese, and the Whites of 1.73, 1.56, and 1.55 per 1,000 live births, respectively. The

Blacks had the lowest rate of 0.58 per 1,000 live births (Panamonta et al., 2015). Thus, the findings have showed that, there are observed differences across continents which might be attributed to ethnic origin, genetic, environmental factors, and methods of ascertainment.

In the United States, at least 1 in 700 babies are born with cleft lip (with or without cleft palate) annually, making it the fourth most prevalent birth defect in the country (Lee et al., 2017). Clefts are prevalent among Latino and Asian children followed by those of the Native American descent. Regionally, there has been a reported incidence of clefts of 0.7 per 1,000 live births (lip and/or palate) in Malawi (Schreiber, 2018). Prevalence of OFCs amongst different populations in Africa vary widely for instance 0.3 in every 1,000 births has been recorded in Nigeria and 1.65 per 1,000 births in Kenya (Wang et al., 2017). Among a group of Sudanese hospital newborns in Khartoum, the prevalence was 0.9 per 1,000 live births (Suleiman et al., 2005). Agbenorku (2005) conducted a study in Ghana amongst the Wudoaba communities and revealed a prevalence of 5 per 1,000 people (Suleiman et al., 2005). Globally, according to the CDC report of 2006, in the United States, 6500 children are born with orofacial clefts each year (Panamonta et al., 2015). The affected individuals suffer various health complications such as difficulties in speech and feeding and physical health problems.

According to a study conducted in Thailand investigating the prevalence of cleft palate between 2012 and 2015 using the orofacial clefts registry and civil registration, revealed a high Cleft Palate prevalence (Fuangtharnthip et al., 2021). A Sri Lankan study conducted by Govanth and Hari (2017) that evaluated speech of 18 patients that had

undergone palate repair found that late repair severely impairs speech production, and that postoperative surgery improved it. There was minimal improvement in speech articulation among patients who underwent surgery alone in the absence of speech therapy.

In the African context, according to Adetayo et al., (2012) visiting surgical teams contributing to cleft care need to make provisions in addressing the socioeconomic at the institutional level (physician) and individual level (patient), financial and infrastructural barriers, and also by placing their focus on patient education. The authors also allude that partnership by these teams with other practitioners in the African region can be done in a more dynamic, effectual and valuable manner in the promotion of cleft care. In Kenya, according to Wanjeri (2018), unrepaired cleft palate is common among the adults in developing countries due to deficient medical services, social and cultural influences, poverty and lack of awareness, fear of some parents/caregivers' surgical operations for children. In developed countries this is different because they do routine surgical treatment with on-going orthodontia, speech and other therapies which is very successful in ameliorating these anomalies.

Surgical repair and rehabilitation care for adults with repaired cleft palate is more complicated with compromised outcomes, with majority of patients having psychosocial problems such as, not being acceptable by peers, some may drop out of school or they may not have attended school due to speech problems, teasing of these patients is common and they are unhappy due to inability to communicate properly, they isolate themselves, and mostly interact with only family members (Murthy, 2009).

Cleft palate surgical repair only restores anatomic continuity. Patients continue to exhibit compensatory mis-articulations post palatal repair. Therefore, speech therapy is very vital after cleft palate repair to deal with compensatory speech habits to enhance quality of life of these adults (Bhuskute , 2017).

1.3 Statement of the Problem

Less attention has been given to persons with cleft palate. Abdurrazaq et al. (2013) identified persons with cleft palate as a special group of handicapped persons whose personal tragedy and problems may well indeed be equal or often exceed those with other body afflictions (Abdurrazaq et al., 2013). These afflictions are usually not of the physical nature but social because the visible defect has a psychological effect on the individual.

Majority of patients with cleft palate will not only have psychosocial problems like lowered self-esteem affecting their rehabilitation and development but also communication challenges thus affecting their quality of life. The incidence of psychological and communicative problems may be higher than what literature suggest, and it is imperative that part of the reconstructive surgery team includes a psychiatrist and speech therapists as part of the panel, as it is important and essential for such cases to be identified so as to enhance patient's outcomes after surgery and other interventions such as rehabilitation. Unfortunately, the existing multispecialty care of these patients focuses on physical rehabilitation while neglecting psychological and communicative aspects of care. In our Kenyan context, cleft palate repair is generally viewed as a cosmetic procedure and is usually done by charity organizations such as operation smile and smile

train. After a week of surgical exercise, patients are left to heal without putting into consideration the role of speech therapy to deal with communicative challenges that result from VPI and compensatory speech errors. However, there is hardly any study that has documented the extent to which VPI affects the quality of life of the population with repaired cleft palate locally. Thus, this study aimed at bridging this gap in investigating the effects VPI on the quality of life of adults with repaired cleft palate within the local Kenyan setting.

1.4 Purpose of the Study

The purpose of the study was to evaluate the effects of VPI on the quality of life of adults with repaired cleft palate at Kenyatta National Hospital.

1.4.1 Objectives of the Study

The following objectives guided the study.

1) To establish the effect of VPI on social interaction of patients with repaired cleft palate
2) To determine the effect of VPI on functional ability of patients with repaired palate.
3) To find out the level of accessibility/availability of speech therapy and counseling services for patients with repaired palate.
4) To determine the role of speech therapy on communication of patients with repaired palate.

1.4.2 Research Questions

The study sought to answer the following research questions.

1. What is the effect of VPI on social interaction of patients with repaired cleft palate?
2. What is the effect of VPI on functional ability of patients with repaired cleft palate?
3. What is the level of accessibility/availability of speech therapy and counseling services for patients with repaired palate?
4. What is the role of speech therapy on the quality of life for patients with repaired palate?

1.5 Assumptions of the Study

The study assumed that adults with repaired cleft palate with VPI anticipate improved social interactions and communication. The study further assumed that speech therapy improves VPI hence impacting on their quality of life.

1.6 Limitation of the Study

The study involved only adults with repaired cleft palate at the Kenyatta National Hospital and excluded those that are treated from other hospitals, and hence the findings cannot be generalized to patients forming this population within the country. Some of the respondents were unwilling to participate in the study and this was mitigated by assuring them of strict adherence to confidentiality and anonymity.

1.7 Delimitation of the Study

The study focused only on the quality of life of adult patients with repaired cleft palate at the Kenyatta National Hospital. It confined itself on persons with repaired cleft palate at KNH and the way it affects their quality of life.

The study was limited to KNH, being the largest referral hospital, there was ample population of persons with repaired cleft palate.

1.8 Significance of the Study

It is critical to patient care to document reported outcomes of cleft palate treatment. Traditionally, outcomes have concentrated more on measurable attributes such photographs, anatomic structure measurements, as well as morbidity and mortality whose importance is unchallenged, but have also left out many unanswered questions. Studies that would include but not limited to speech, self-image, quality of life as well as aesthetics would provide more in outcomes assessments. This study may benefit the multidisciplinary team, i.e., maxillofacial surgeons, plastic surgeons, orthodontists, in understanding the relevance of quality of life for patients undergoing treatment at the facility, and how they can incorporate it as part of treatment. This can lead to creation of better protocols in terms of management and care for patients in adopting coping strategies with their social life. The study may be useful to various stakeholders in the ministry of health by providing a framework to deal with cleft palate and adopt better treatment strategies for persons who have undergone cleft palate repair. The study findings may also be useful for those interested in pursuing this area on the quality of life for such patients by serving as a reference point.

1.9 Theoretical Framework

This study was guided by Self-Verification Theory of Hardin and Higgins (Hardin & Higgins, 1996). According to this theory, there is a set of firm beliefs and feelings about how people perceive themselves before the world, and how they want to be understood and known which is dependent on how they judge themselves. The human face is significant and is eloquent, and just by looking at each other forms some basic form of conversation, as it is the first thing wherever people meet that is the center of focus. It is the primary source for vocal communication, expression of emotions, and also reveals personality traits. Depending on one's culture and values, certain visible and physical characteristics can evoke reactions such attraction or repulsion. McLeod (2016) stresses that positive and negative behavior is learned from interactions within the environment majorly through learning. Individuals tend to control their behavior through self-regulation. Self-regulation necessitates self-observation, judgments about ourselves and our surroundings, and self-response. People have an impact on the world around them and are impacted by it. However, patients with VPI are faced with major challenges in their speech which is essential and define high level of efficiency. Depending on one's culture and values, certain visible and physical characteristics can evoke reactions such attraction or repulsion.

Interpretation and misinterpretation of personality made on the basis of the appearance of another is a common occurrence. While evaluation of another may be formed by conscious interpretations, unconscious interpretations or misinterpretations play a predominant part in forming an image of the personality itself (Gustav, 1949a).

The theory was useful for determining the predictive behavior of individuals with repaired cleft palate and its impact on their social interactions as well as addressing quality of life, as it examines the complex interactions that result in behavior that is likely to be a hindrance in socializing with others.

1.10 Conceptual Framework

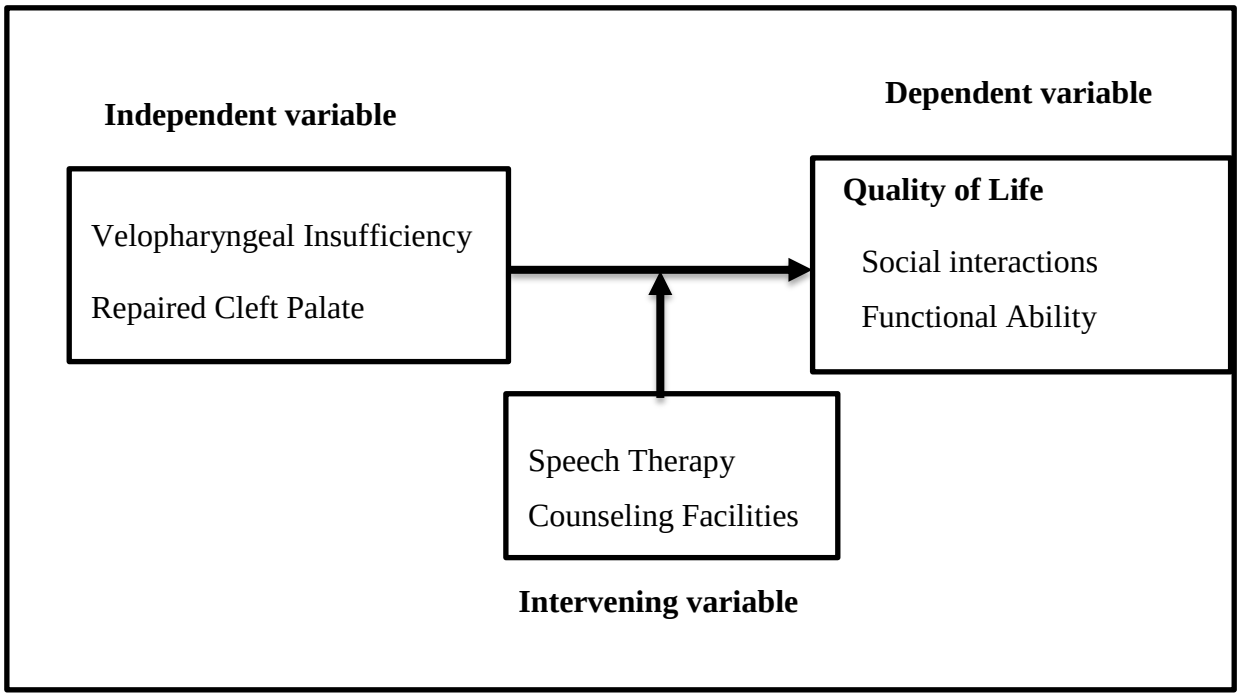

Figure 1.1: Conceptual Framework

The figure illustrates the interrelationship of the variables of the study. From the conceptual framework, the independent variables are velopharyngeal insufficiency and repaired cleft palate, while the dependent variable is quality of life which results to improved social interactions/poor or limited social interactions, and improved functional ability/poor or limited functional ability, depending on the level of intervening variables. The relationship between dependent variables and the independent variable is intervened

by availability or access to speech therapy, and counseling facilities. Patients with repaired cleft palate suffer VPI, (Independent variables), and for quality of life to occur therefore, intervening variables (speech therapy, counseling) help to correct compensatory speech errors.

1.11 Operational Definitions of Terms

Cleft Palate: Refers to an opening on the roof of the mouth due to failure of the palatal shelves to come together from either side of the mouth and fuse during the first months of embryonic development (Cashin-Gurbutt, 2018).

Cleft: it is an opening or usually an abnormal fissure that results from the failure of the parts in fusing during the stages of embryonic development (Kallen, 2014).

Hard Palate: the bony front section of the upper part of the mouth (Bessell et al., 2013).

Soft Palate (Velum): it the muscular part of the roof of the mouth, it is directly behind the hard palate, and it is moveable (Kummer, 2013).

Speech Intelligibility: The degree of clarity of a speaker's verbal communication as perceived by the listener (Johanisson, Lohmander, & Persson, 2014).

Pharyngeal walls: Refers to the walls of the throat, anterior and posterior (Kummer, 2013).

Velopharyngeal Insufficiency (VPI): this refers to the structural disorder which results to a malfunction of the velum from making appropriate closure with the posterior pharyngeal wall so as to close off the nose amidst speech (ASHA, 2012).

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

The chapter discusses the literature on velopharyngeal insufficiency on the quality of life among adults with repaired cleft palate, and present the findings based on their review in order to establish the gaps emanating from literature.

2.2 Velopharyngeal Insufficiency and Social Interaction of Patients with Repaired Cleft Palate

Social interaction is influenced by different factors. Patients with repaired cleft palate have major challenges which are based on their speech. According to Kummer (2013), individuals having a history of cleft palate or velopharyngeal dysfunction highly demonstrate a combination of speech sound errors, nasal emission as well as hyper nasality. A study done by Hopper et al. (2014) revealed that velopharyngeal insufficiency after cleft repair necessitates additional surgery which aims at correcting this error. However, it is imperative to understand that individuals having this condition have a reduced social interaction as a result of speech challenges.

Patients whose cleft palate have been repaired often suffer from VPI which affect their social scene in terms of communication and interaction with others (Bhuskute et al., 2017). This is noted in a study done by Kristin (2017) on speech and language, where the author suggests that cleft teams must recognize that problems in speech, language, and reading are probable indicators for psychological risk for such patients. Therefore, it is important to note that psychological health is dependent on self-perception and social

skills as they influence the manner in which they interact with others or they might experience social ostracism (Bull & Rumsey, 1988). Feragen et al. (2017) affirmed that there is need to understand the problems associated with speech, language and reading since they are essential indicators for psychological risk for patients with this condition. Thus, psychological challenges create a limited basis in making conclusive decisions relating to their self-confidence and social skills. They experience difficulties in participating in social activities due to low self-esteem and most people do perceive such individuals as less intelligent or socially unacceptable. These sentiments are also echoed by Kinter, (2018) who found that patients with repaired cleft palate while still experiencing velopharyngeal insufficiency have difficulties in participating in social activities while also maintaining a low self-esteem.

Individuals with repaired cleft palate suffer from VPI and their social nature of communication is affected. This affects their self-concept. Importance of having a good self-concept is widely accepted, and a major component of self-concept is one's appearance or attractiveness (Leonard, Brust, Abrahams, & Sielaff, 1991). Thus, individuals with cleft palate often have additional sense of low self-esteem due to deformity. Those with repaired cleft palate talk with heavy nasality. This makes them shy away from talking in public. Their social life is therefore affected and becomes withdrawn (Ndung'u & Kinyua, 2009).

According to a study done on overview of psychosocial issues of patients with cleft palate, revealed that teasing is one of the noteworthy predictors of poor psychological performance (Sousa, Devare, & Ghansani, 2009). A study done on social stigma and

cleft disorders revealed that those with cleft palate are discriminated negatively by being labeled as being different from normal. An individual attitude towards their body image is related to how they think, behave and feel about themselves on their physical appearance, while the links between physical attractiveness and acceptance in the society show the shortcomings that individuals with cleft palate undergo (Sousa Devare, & Ghansani, 2009).

A psychosocial outcome of operated cleft palate patients has been discussed extensively in literature but very little has been discussed on their psychological profile. Part of the life of these individuals is teasing which can be a cause of unhappiness due to the incapacity to communicate, as these only makes them socially recluse and interact only with the family members (Bhuskute et al., 2017).

Despite there being advances in the surgical procedures and the inherent advantages of having repairs done at a younger age, such individuals still suffer psychological strain particularly during their adolescent years (Gussy & Kilpatrick, 2006). Most studies have largely focused more on psychological issues related to VPI and cleft palate and limited studies on social interaction of this population. Thus, this study sought to investigate effects of VPI on the social interaction of persons with VPI after cleft palate repair.

2.3 VPI and Functional Ability of Patients with Repaired Palate

Velopharyngeal Insufficiency (VPI) refers to the inability of the soft palate and pharyngeal walls coming together to create a seal during speech production (Moon & Kueh, 2015). The correction of this condition is dependent on the timing when it is

recognized and is best done before the child is of school going age to ensure proper performance.

Speech is a difficult form of human behavior, which is based on the organic structure of the central nervous system and orofacial structure. It is also dependent on other factors such as various developmental, environmental and psychosocial, and if any of the structures fails in their function, they have a direct impact on the oral communication. The ability to achieve adequate velopharyngeal closure is a prerequisite to the activities that involve swallowing and speaking, as they invoke multifaceted motor aptitudes that rely on varied muscles in the upper aero-digestive tract. Velopharyngeal movements used in speech differ from those employed during swallowing, since there is good closure during swallowing from these patients as opposed to obtaining adequate closure during speaking (Luke, 2018). Some patients develop hyper nasal speech and compensatory mis-articulations despite the repair of cleft palate restoring anatomic continuity. The development of hyper nasal speech is as a result of the repaired cleft palate, velopharyngeal incompetence or oronasal fistulae.

Rhodes (2009) stressed that *tonsillar* hypertrophy is another factor that may limit velopharyngeal closure. Some of the known manifests of VPI are hyper nasality, decreased vocal intensity, short phrases, imprecise consonant production, and nasal emission. VPI may also be caused by neurogenic paresis or any other physiologic dysfunction. A speech pathologist makes a diagnosis after a comprehensive assessment through procedures such as *nasoendoscopy* with or without *video fluoroscopy*.

Biaviati (2017) in his review of post-operative patients noted that speech therapy improved velopharyngeal function due to articulation errors or when the velopharyngeal dysfunction (VPD) is minimal. The study further found out that, structural defects correction through surgery in the velopharyngeal port scarcely changes the functioning by default, as articulation problems may still endure after surgery. From these evaluations of post-surgical speech and resonance, it can therefore be noted at this point that speech therapy is necessary.

A study done on velopharyngeal function and speech by, Palomares, Alvarez, Giugliano & Villena (2013), reviewed a high success in correction of VPI after speech therapy intervention. Young adults involved in this study presented with VPI. The study concluded by proposing that, implementation of the protocol can provide a better guide and treatment for persons with VPI. Thus, an appropriate surgical and SLP intervention can be designed, improving outcome. Hence, this study investigated functional abilities among persons with VPI after cleft palate repair.

2.4 Accessibility/Availability of Speech Therapy and Counseling Services for Patients with Repaired Cleft Palate

There are few adults with unrepaired cleft palate in developed countries since medical services as well as health awareness amongst the patients are significantly advanced. This contrasts with the developing countries where public awareness or even the availability of treatment is minimal where the age of patients seeking management usually varies from some days to even midlife (Murthy, 2009). When patients are motivated and followed up for speech therapy, VPI correction can be successfully done (Hobbs, 1991). A different

approach to treatment of older patients is demanded, as there is a need to study their surrounding environment, psychological make-up, financial and logistical factors, as well as demands on their life in the planning of their treatment (Murthy, 2009).

The main difficulty about following a team-based approach for the treatment of individuals with CP in developing countries is that the professionals who represent the cleft care team are either unavailable or limited in number. The speech-language therapy services are often also not available or extremely limited in developing countries D'Antonio & Nagarajan, 2003; Sell, 2007; Gopalakrishna & Agarwal, 2010). To overcome some of the issues, International teams sponsored by charity organizations provide free surgical interventions in countries where the facilities for repair of the cleft are not available, and also train the professionals for cleft care (Conversion Academic, 2018).

Speech intelligibility among persons with cleft palate after repair is relatively low as a result of the associated articulation disorders (compensatory errors). Consequently, speech therapy may be necessary for increasing speech intelligibility. Persons with repaired cleft palate who lack timely speech therapy interventions would have moderate speech intelligibility, and therefore such persons are recommended to receive speech and language therapy after undergoing corrective surgery (Safaican, Jalilerand, Ebrahimipour Aleshirin & Hiradfar, 2017). As a result of the related articulation difficulties, speech intelligibility among people with cleft palate is relatively low following correction. As a result, speech therapy may be required to improve speech intelligibility. People with healed cleft palates who do not receive timely speech therapy will have moderate speech

intelligibility, hence it is suggested that they have speech and language treatment after correction surgery (Howard & Lohmander, 2013).

According to Hodgkinson (2005), patients with cleft palate should have psychological care, and this should be at the beginning as from the time of diagnosis which may be before birth where there is involvement of psychologists within the cleft team. This helps in in the management of this group of people at all levels, to deal with concerns such as, low self-esteem, underachievement, frustration of low speech intelligibility. His study recommended that all members of cleft team should consider addressing the psychosocial needs of the patients under their care before and after surgery. According to Park et al. (2019) in a study that sought to establish the availability of speech therapy and counseling, it was determined that patients with cleft palate should have psychological care, and this should be at the beginning as from the time of diagnosis where there is involvement of psychologists within the cleft team. This aids in the management of this group of people at all levels.

In developing countries, the major hurdle in using a team-based approach for treating people with Cleft Palate is that the experts that make up the cleft care team are either unavailable or in short supply. In third world nations, speech-language therapy services are either unavailable or severely limited (Bessell et al., 2013). In addition, to address some of the concerns, international teams funded by charitable organizations give free surgical operations in countries where cleft repair facilities are lacking, as well as training for cleft care professionals (Alighieri et al. 2020). This study, therefore sought to

establish the availability or accessibility of speech therapy and counseling services for patients with repaired cleft palate.

2.5 Role of Speech Therapy on Communication of Patients with Repaired Palate

Cleft palate is the leading craniofacial malformation, and even after repair, there may be persistent symptoms that affect speech, nasal breathing, voice, dentition appearance and quality of life. Cleft palate affects the musculature response for coordinated closure during speech. Even after surgical repair residual deficits often remain and this affects social interactions and communication. The quality of life of individuals with cleft palate is usually under threat for various reasons ranging from ineffective social connection, different in social appearance, repeated surgeries and others. Speech therapy corrects compensatory articulation errors on cleft patients postoperatively (Michael, 2017). Kara et al. (2020) stressed that after cleft palate repair, some people are at increased risk of VPI since it occurs when the soft palate is short and cannot reach the back of the throat. This makes it challenging for individuals to create certain speech sounds, particularly those that necessitate closing the palate. These 'cleft type' speech sounds might make it difficult to understand the individual, necessitating speech therapy.

Most persons will still demonstrate delayed development in language, speech and sound and also have typical cleft palate speech despite timely intervention. After palate repair, some people will have velopharyngeal insufficiency (VPI), as this occurs when the soft palate is not long enough to reach the back of the throat to make a firm seal to facilitate desirable nasal exhalation during speech. This makes it difficult for them to make certain speech sounds, especially those that require the palate to be in the closed position. These

‘cleft type’ speech sounds can make the individual difficult to understand and they will need speech therapy. If there are any concerns regarding nasal speech, further tests may be required (Jones, 2003).

Spoken language usually contains oral and nasal sound segments. For successful speech production it is vital that the capacity to control air properly throughout the aero tract in harmony with articulatory and phonatory processes. Speech problems emerge where inadequate structure or function of the velopharyngeal port and the soft palate fail to permit this which is common among individuals having a cleft palate (Sara &Annete, 2011).

Following surgery, the speech production challenges with VPI do not automatically wane (Moon et al 2015), and the associated difficulty affects phonation and, resonance as well as articulation(Peterson-Falzone et al, 2005). The characteristics of persons with cleft palate are excessive nasality or hyper nasality (Kuehn &Moller, 2000). According to a study done on individuals with cleft palate revealed that speech development post-surgery begins to be normal on some of the individuals, while some achieve age appropriate speech after a period of speech intervention (Chapman, Black, Girotto, & Oppenheimer, 2009). The main contributions that have revolutionized cleft palate surgery over the years more often than not do not contain representatives from the speech world (Jackson, Moreira-Gonzalez, Rogers, & Beal, (2004).

According to a study done on delayed hard palate closure, where a speech therapist was an author, revealed that individuals with delayed hard palate closure suffer severe speech

problems both before and after closure of the hard palate (Witzel et al.1984). The same study revealed that in many centers around the world the speech language professional (SLP) does not pursue or is not permitted an equal role with the plastic surgeon and the orthodontist in the decision for palatal surgery. The researcher further revealed that, if an SLP had been actively involved patients may not have undergone a series of surgeries. The researcher concluded by proposing the inclusion of an SLP in the decisions regarding palatal surgery (Witzel et al. 1984).

The extensive research on the area of cleft palate suggests that surgery is fundamental towards development and attainment of adequate speech so at to offer individuals with cleft palate the velopharyngeal function that will enhance their speech or typical verbal communication (Botticelli et al., 2019). The impact of incorporating speech therapy alongside surgery to facilitate speech has been the focus of this literature review with an objective to understand how the combination improves social growth and ultimate improvement of their quality of life. The study thus emphasized on the need to understand the role of speech therapy on communication of patients with repaired palate.

2.6 Summary of the Literature Review

The studies have so far highlighted on psychological issues affecting patients with cleft palate and velopharyngeal insufficiency and limited studies on communication and social interactions. There lacks an assessment and understanding of the simultaneous effect of facial disfigurement as well as speech challenges on specific adjustment indices including depression, behavior, anxiety and self-perception. For these individuals to develop and maintain self-beliefs, physical attractiveness plays a major role. There is a preference for

attractive persons that influence their self-esteem and social competence according to research, and across all age groups, being physically attractive is a desirable characteristic. It has been demonstrated to be socially indispensable in aspects such as building relationships in life across all levels: school, work, extended families, peer groups, courtships etc. Social acceptance largely relies on one's physical look. These associations between physical beauty and societal acceptability point out the difficulties faced by individuals affected by cleft palate. This study therefore seeks to determine the effect of VPI on social interaction of patients with repaired cleft palate, as well as their functional ability. It also seeks to determine the level of accessibility and availability of speech therapy and counseling services, and the role of speech therapy on their quality of life.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

The chapter highlights the research design, variables, research methodology, and location of the study and target population. It also presents the sampling techniques and sample size, and research instruments to be employed in the study. The chapter closes with pre-testing/pilot study, validity and reliability tests, data collection techniques, data analysis and logistical and ethical consideration.

3.2 Research design

The study used a case study design which employed both the quantitative and qualitative approaches (Ryan & Branscombe, 2013). The researcher sought to analyze the variables applicable to the issue under study. Case study was used because it provides a detailed investigation of individuals (Gama & Alves, 2021). This design was also appropriate for the choice of research tools used. The detailed qualitative accounts produced in the case study both in exploration and the description of the data in real life environment and in explaining the complexities of real life situations which may not be captured through experimental or survey research (Zainal, 2007).

3.3 Study Variables

Variables refer to characteristics of cases, attributes or qualities of cases that are measured and recorded (Orodho, 2009).

Independent Variables of the study included Velopharyngeal Insufficiency, Repaired Cleft Palate

Intervening Variables included Speech Therapy, counseling services

Dependent Variable was Quality of Life among patients with repaired Cleft Palate: social interaction (improved/poor or limited social interaction), Functional ability (improved/ limited functional ability)

3.4 Location of the study

The study was conducted at Kenyatta National Hospital, Nairobi City County. Kenyatta National Hospital is the largest referral Hospital in East and South of Sahara. Being the largest referral Hospital, it has the largest number of adult patients with cleft palate having been referred from all over the country for treatment, hence the researcher was able to get adequate sample from the population of those with cleft palate.

3.5 Target Population

This study targeted 220 adults both males and females with repaired cleft palate at Kenyatta National Hospital Nairobi City County, 2 Maxillofacial Surgeons and 1 Speech and Language Therapist. This was achieved by reviewing their clinical notes in the maxillofacial clinic and face to face interviews during scheduled review appointment.

3.6 Sampling Techniques and Sample Size

3.6.1 Sampling Techniques

The researcher used purposive sampling to choose adults, both male and female with repaired cleft palate. In purposive sampling, the researcher decided the cases to be included in the study based on their judgment (Ary, Jacobs ,Sorensen, & Walker, 2014).

3.6.2 Sample Size

A sample is a subset of a population (Desu, 2012). The sample size comprised of 22 adults (both male and female) with repaired cleft palate. Gay, (2016), suggested that researchers with large sizes of study populations between 101 and 1,000 should have a sample of 10%. The sample size was 10% of a population of 220 adults with repaired cleft palate. Census technique was used to select a sample size of 2 maxillofacial surgeons and 1 speech and language therapist.

Table 3.1: Sample Size

Group	**Target population**	**Percentage (%)**	**Sampling technique**	**Sample size**
Adults with repaired cleft palate	220	10%	Purposive sampling technique	22
Maxillofacial surgeons	2	100%	Census	2
Speech and Language Therapist	1	100%	Census	1
Total	**222**			**25**

Source: Kenyatta National Hospital Records (2019)

3.7 Research Instruments

3.7.1 Questionnaires

The researcher used questionnaires to collect data. A questionnaire provides the respondents with an opportunity to express their beliefs, experiences, feeling, attitudes or

perceptions. Questionnaires used in the study had a list of structured questions with clear instructions and spaces for answers designed to purposely meet the demands of research objectives. The sampled adults with repaired cleft palate were subjected to structured questionnaires.

3.7.2 Interviews

Interview guide was used for Maxillofacial Surgeons and Speech and Language Therapist responded based on the methods or ways used to improve quality of life of patients post cleft palate repair. The interviews consisted of structured question guides designed to review the required information.

3.8 Pilot Study

Mugenda (2009) explained piloting as the disciplined exercise of presenting research instruments to a different audience that has relatively similar characteristics with the actual sample to determine their reliability and validity of the instruments. Pilot study was necessary to ensure that the respondents give feedback on clarity of questions, language, content, relevance of items, flow of questions layout, and length before the actual study. . The pilot study was carried out at Kijabe Mission Hospital. The location was chosen because this is where one of the major charity organizations (Smile Train organization) provides corrective surgery for individuals with cleft palates hence the researcher was able to get adequate respondents. The subjects used were different from those who participated in the actual study.

3.8.1 Validity of the Research Instrument

Research instruments validity was established through seeking the opinion of the University supervisors on the content, level of language, ambiguity clarity, alongside other qualities to ensure that the tools are comprehensive and that they were able to measure the variables intended for the study.

3.8.2 Reliability of the Instrument

According to Csikszentmihalyi and Larson (2014), reliability refers to the degree of consistency of a research tool such that yields similar result after repeated trials (Heale & Twycross, 2015). The researcher employed test and retest technique, whereby the same questionnaires was administered at an interval of two weeks to the same group of respondents and compare the outcomes thereafter. Caution was taken to ensure that the people included in the pilot study were not included in the final study. Mugenda (2009) cautioned that subjects in the actual study should not be used in the pre-test. Consistent results under the same condition showed that the research instruments were reliable (Thyer et al., 2019). Cronbach Coefficient Alpha test was used to test the reliability of the measures in the questionnaire.

The findings from the analysis found that Cronbach alpha was 0.668. This shows that the data tool as reliable >0.6. A generally acceptable rule shows that alpha level between 0.6 – 0.7 highlights an acceptable level of reliability. Thus, the focus on the data obtained to decide regarding the assessment of VPI among patients with repaired cleft palate is effective.

3.9 Data Collection Techniques

Prior to data collection a consent letter was sought from the Kenyatta University and research permit from Kenyatta National Hospital/UoN Research and Ethics committee. Two research assistants were hired and trained on how to communicate and ensure clarity of information to respondents, anonymity, ethical issues on confidentiality and assist in data collection exercise. The researcher collected primary data using questionnaires and review of patients' clinical notes at the maxillofacial clinic at Kenyatta National Hospital for patients with cleft palate repair in order to obtain in-depth information. According to studies, adults with repaired cleft palate suffer.

Primary data was collected using a well-structured questionnaires and interview guide. During the actual data collection, the researcher distributed questionnaires to the respondents with the help of two research assistants to fill and return to the researcher, a process that took three days. Interview schedules for two maxillofacial surgeons and one speech therapist, were administered with the help of research assistants within a period of two days using structured question guide.

The researcher was present during data collection exercise to clarify any possible ambiguities during the filling of questionnaires.

3.10 Data Analysis

Data analysis refers to the procedural organization and manipulation of data to unmask trends in a given set of observations and offer a ground to draw conclusions (Cresswell, 2012). The collected data were coded and analyzed according to stated objectives and research questions.

The quantitative data was analyzed using Statistics Package for Social Sciences Version 24 (SPSS V. 24) and summarized as frequencies and proportions. Where applicable, appropriate graphs, charts, and tables were used to illustrate patterns and show trends. The qualitative data was then subjected to content analysis with the use of Atlas/Ti and summarized into themes and presented in prose.

3.11 Logistical and Ethical Considerations

The researcher sought for an introduction letter to carry out research, from the Dean Post Graduate School and Ethics Review Committee, Kenyatta University. This letter was used to facilitate the acquisition of research permit from KNH Ethics and Research Committee. The researcher obtained permission and clearance from National Commission for Science, Technology and Innovation (NACOSTI) in order to carry out research and collect data.

Only participants who gave informed consent were included in the study and they were requested to sign informed consent forms before enrollment to the study. The participation in the study was voluntary. Respondents who felt uncomfortable to participate in the study could exit.

Confidentiality was always maintained, and the participants did not incur any extra cost. Research data was only made available to the researcher and the research assistants.
Respondents were accorded the same treatment and were informed of the purpose of the study and how its findings will benefit them.

CHAPTER FOUR

PRESENTATION OF FINDINGS, INTERPRETATION AND DISCUSSION

4.1 Introduction

This chapter presents the findings, interpretation and discussion according to the set, objectives and research questions. The study was designed to evaluate the effects of VPI on the quality of life of adults with repaired cleft palate. The set objectives were to establish the effect of VPI on social interaction of patients with repaired cleft palate, to determine the effect of VPI on functional ability of patients with repaired palate, to find out the level of accessibility/availability of speech therapy and counseling services for patients with repaired palate and to determine the role of speech therapy on communication of patients with repaired palate.

4.2 General and Demographic Information

4.2.1 Questionnaire and interview return rate

Questionnaires were distributed to adults (both male and female) with repaired cleft palate in Kenyatta National Hospital, Nairobi Kenya. A total of 24 questionnaires were issued to understand the effect of VPI severity on functional ability and social interaction. A total of 22 fully filled questionnaires were returned indicating a 92% response rate which is appropriate in providing an understanding on research problem. The rate of return is summarized in table.

Table 4.1 Response rate

Gender of Respondents	Frequency	Percentage
Total Questionnaires	24	100%
Returned Questionnaires	22	92%

From Table 4.1, it is evident that there was a smaller sample population from which the researcher could select from giving only a sample size of 24 participants. This is attributed to the sensitive nature of the issue as well as very few individuals with cleft palate seeking healthcare to correct the condition. However regardless of the small sample size, the data obtained was enough to help in making inferences based on the research questions investigated in the study. Two interviews were conducted to help understand the level of accessibility/availability of speech therapy and counseling services for patients with repaired palate.

4.2.2 Demographic characteristics of respondents

In terms of age, nine of the respondents were aged between 26 and 35 years. Out of 22 respondents 12 had tertiary education, 11 of the respondents were single while there was equal number of male and female. The figures below provide a summary of the respondent's demographic characteristics.

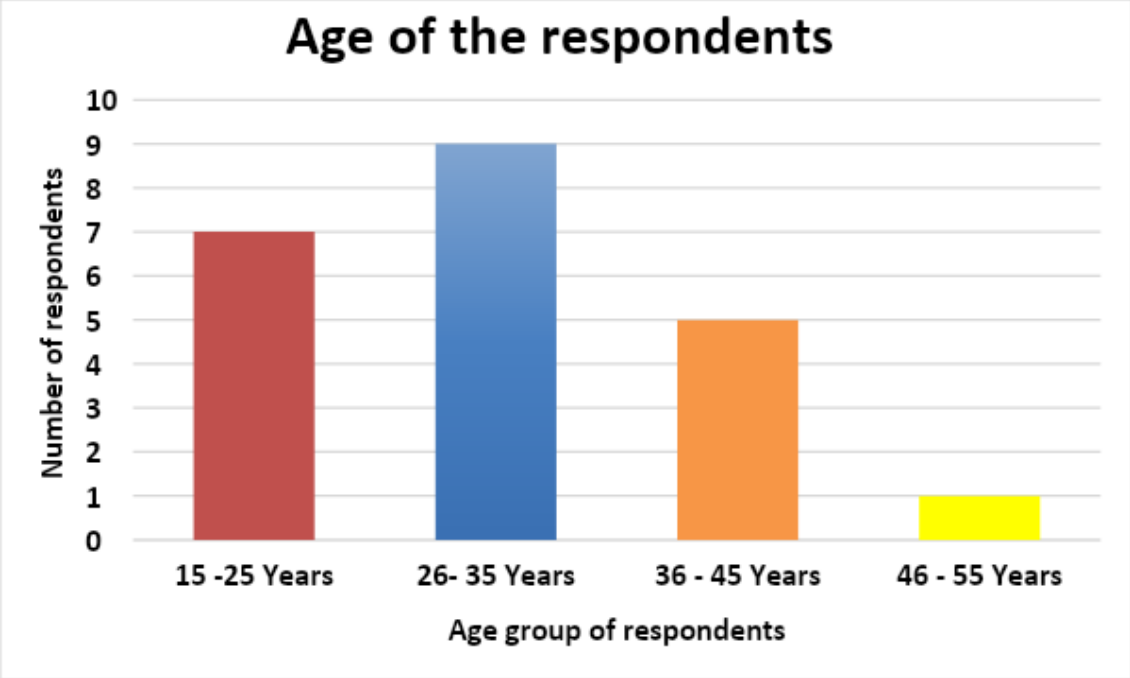

Figure 4.1 Age of the respondents

Out of the 22 respondents included in the study,7 were aged between 15 and 25 years, 9 were aged between 26 and 35 years,5 were aged between 36 and 45 years, while only one respondent was aged between 46 and 55 years. The findings from the study are similar to a previous study by Marazita (2012) who found that majority of individual who seek cleft palate repair are youths because of difficulty in socializing as well as developing new relations. Murthy (2009) also found that most of individual who seek cleft palate repair are below 40 years. Building relationships and communication is a major challenge to majority of cleft palate patients especially in their younger years from adolescent to younger adults. However, Leu et al., (2021) found higher rate of cleft palate repair among children. This was mainly because most parents or caregivers seek to transform the wellbeing of their children early in the hope of attaining better health outcome.

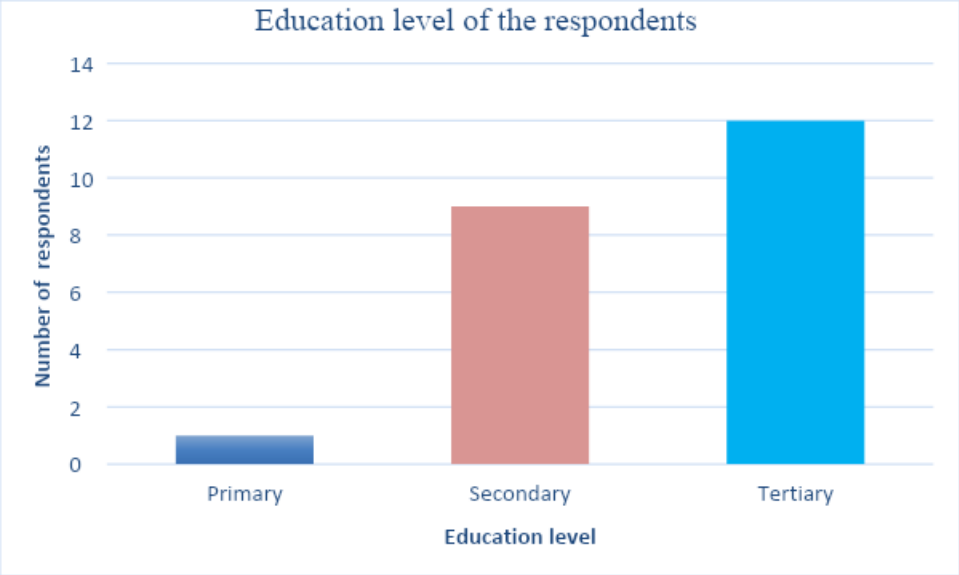

Figure 4.2: Respondent's education level

As indicated in Figure 4.2, 12 had tertiary education level while only one of the respondents had primary level education. The findings show that most of the respondents who had cleft palate repair are post-secondary school patients. This could be attributed to inadequate knowledge and awareness on cleft palate treatment among the general public where only those who have the knowledge can seek cleft palate treatment. The findings support previous results from Howard (2011) which highlighted that undertaking the cleft palate repair is mainly determined by individual knowledge of their condition.

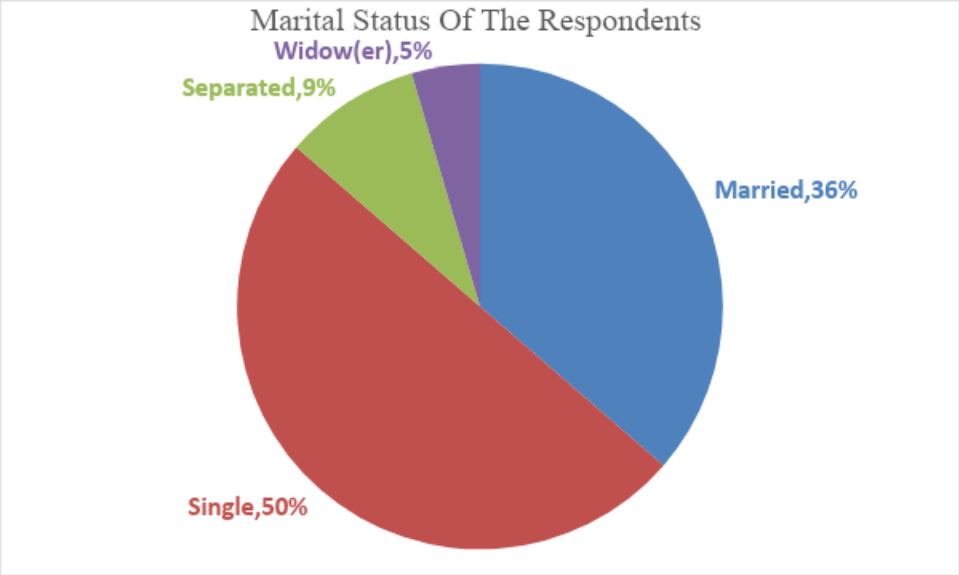

Figure 4.3 Respondents Marital Status

Half of the respondents (50%) were single, 36% were married and 9% of the respondents were separated. The findings show that most of the respondents were single despite the fact that the majority were aged between 26 and 35 years of age. These findings are similar to those of a study by Bhuskute and Tollesfon, (2017), which revealed that most of cleft palate patients are unable to develop relationships hence have lower self-confidence and prefer to stay alone. This has contributed to the fact that majority of them are single.

4.3 Effect of VPI on social interaction of patients with repaired cleft palate

The study sought to assess the effects of VPI on social interaction among patients with repaired cleft palate. Five important aspects were assessed focusing on individual perception about their speech.

4.3.1 Individual perception of speech

The researcher sought to explore the opinions of the respondents in regard to their feelings based on their speech. Results are presented in Table 4.2.

Table 4.2 Respondents individual feeling on based on their condition

	Almost n (%)	**Sometimes n (%)**	**Often n (%)**	**Always n (%)**
I am teased because of the way I talk		4(18.2%)	7(31.8%)	11(50)
I get sad because of how I talk		4(18.2%)	2(9.1%)	16(72.7%)
I get frustrated or give up when I am not understood		2(9.1%)	3(13.6%)	17(77.3%)
I am shy because of how I talk		2(9.1%)	9(40.9%)	11(50%)

As illustrated in table 4.2 above, half (50%) of the respondents stated that they are always teased because of the way they talk, two thirds (72%) of the respondents highlighted that they are always sad because of how they talk, 77% always feel frustrated and give up when they are not understood while 50% of the respondents feel shy because of how they talk.

These findings concur with Leonrad et al. (1991) who stressed that individuals with cleft palate have low sense of self-esteem because of how they talk. Ndung'u and Kinyua (2009) also highlighted that individuals with cleft palate tend to remain withdrawn and have difficulties in forming relationships because they feel shy and fear that they might not be understood at all. However Sousa et al., (2009) found contrasting results which revealed that patients with cleft palate repair through surgery had increased self-esteem,

self-confidence and satisfaction with appearance. Thus, surgery can be used in improving esthetic appearance as well as in improving psychological development of adolescents.

4.3.2 Speech Perception by others

The researcher further sought to find out from the respondents how others perceived their speech. The findings are illustrated in Table 4.3.

Table 4.3: Speech perception by others

	Almost n (%)	Sometimes n (%)	Often n (%)	Always n (%)
I am treated like I am not a smart person because of how I talk	2(9.1%)	7(31.8%)	7(31.8%)	6(27.3%)
Others ignore me because of how I talk		7(31.8%)	5(22.7%)	10(45.5%)
Others do not like to talk on the phone with me because of how I talk	2(9.1%)	4(18.2%)	2(9.1%)	14(63.6%)
My family or friends tend to talk for me	1(4.5%)	11(50%)	4(18.2%)	6(27.3%)

As illustrated in Table 4.3 above, seven of the respondents felt that sometimes or often they are treated as if they are not smart because of how they talk, 10 of the respondents stressed that they are ignored by others based on how they talk. More than half (14) of the respondents stated that others do not like to engage them on phone because of how they talk always. In addition, 50% stressed that sometimes they are engaged by family members and friends. Sousa, Devare, and Ghansani (2009) highlighted that cleft palate

patients are highly discriminated by others because they are not perceived to be normal. Discrimination is mainly associated with how they behave, think and perceive themselves. These elements are essential in defining individual physical attractiveness and acceptance in the society. Bhuskute et al (2017) also stated that majority of cleft palate patients are more comfortable with their family members who they believe understand them better based on their uniqueness. These findings however are different from those found by Amick et al., (2017) who found that self-esteem and self-confidence of individuals with speech problems is not associated with social interaction and engagement. Personal perception was identified as a major factor that defines their wellbeing and confidence.

4.3.3 Challenge in making friends

The study sought to find out the challenges experienced by the respondents in making friends. Figure 4.4 shows the responses as received from the participants.

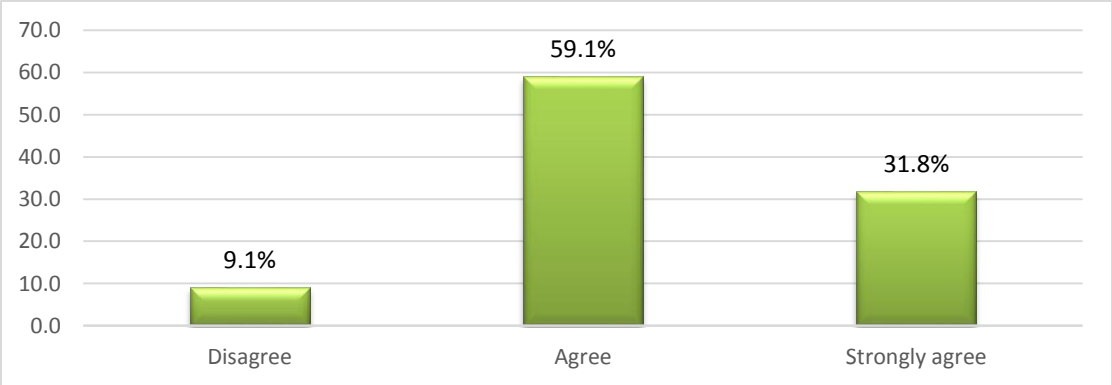

Figure 4.4: Respondents assertion on whether it is challenging in making new friends

As identified in figure 4.4, more than half (59%) of the respondents agreed and 31.8% strongly agreed that is challenging to make new friends. Making friends among cleft

palate patients is mainly determined by the ability to communicate in a manner that can be understood. These findings concur with Ha et al., (2015) who stated that majority of cleft palate patients perceive themselves negatively which limits their ability to interact and form relationships.

4.3.4 Challenges with Social interactions

According to the study findings, a social interaction is one of the most common problems experienced by persons with cleft palate. Figure 4.5 illustrates personal opinions of the respondents on how much their social interaction abilities are affected by VPI.

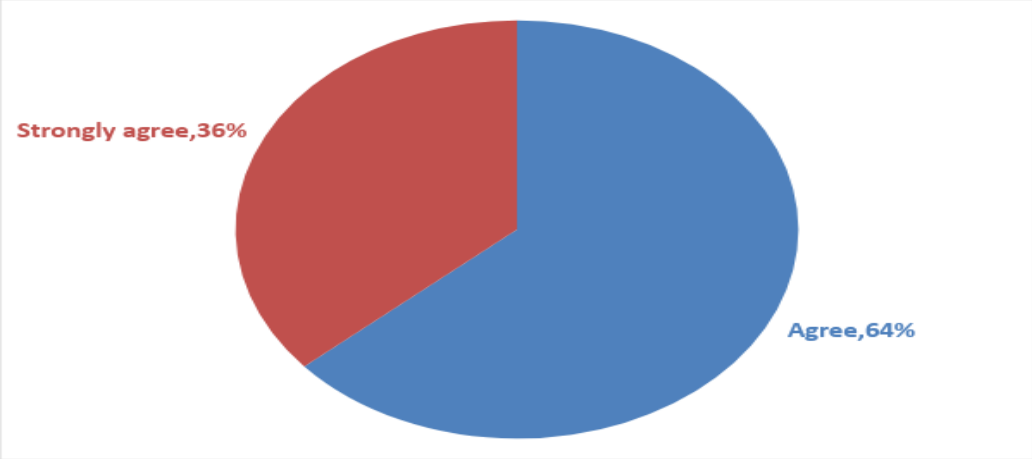

Figure 4.5: Respondents assertion on whether social interactions are enjoyable

Out of the 22 respondents as shown in the Figure 4.5 above, 14 agreed and 8 strongly agreed that they do not find social interactions enjoyable because of difficulty in communicating as represented in figure 4.5. The fact that majority of cleft palate patients are withdrawn, it makes it difficult to enjoy social interactions because they are required to talk more. Devare and Ghansani (2009) argued that psychosocial issues of cleft palate patients is mainly because they are unable to communicate effectively as well as being

teased by others which make it difficult to have a successful conversation in social gatherings. The same study also found that social stigma is a major predictor of the level of interaction among cleft palate patients. Ndung'u and Kinyua (2009, stated that those with repaired cleft palate talk with heavy nasality, and this makes them shy away from talking in public.

4.3.5 Difficulties in initiating positive interactions

The researcher sought to find out difficulties experienced by the respondents' in establishing positive interactions. The findings are as shown in Figure 4.6.

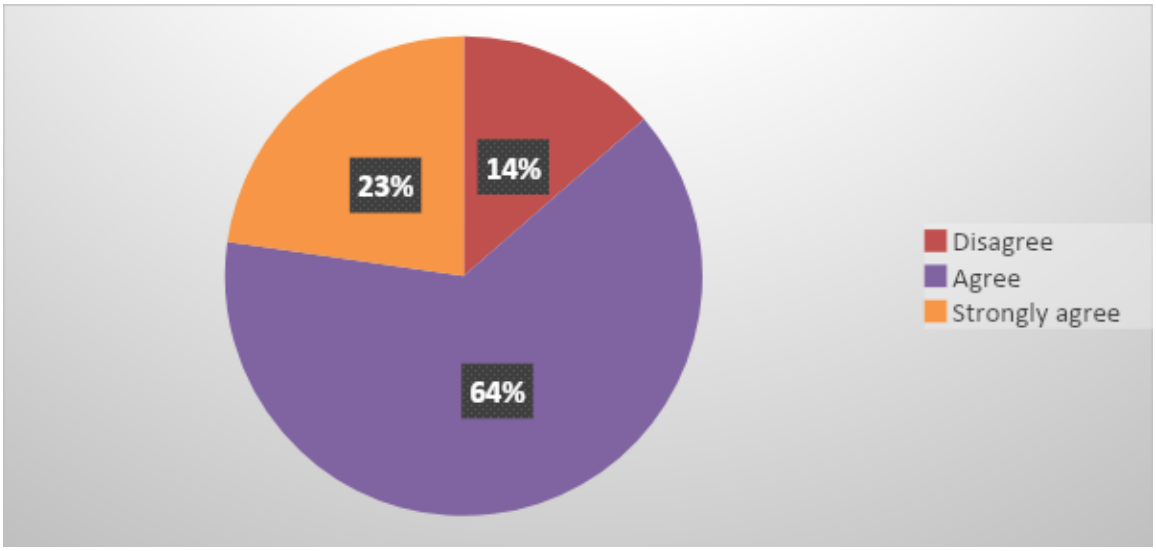

Figure 4.6 Respondents understanding on whether they face difficulties in initiating positive interactions

From figure 4.6 above, 63% of the respondents agreed, and 23% strongly agreed that they find difficulties in initiating positive interactions. Initiating interactions requires confidence and understanding of the existing relationship. Feeling comfortable is essential in having successful positive interaction. However cleft palate patients tend to be more withdrawn and find difficulty in developing relations (Ndung'u & Kinyua 2009).

Bhuskute et al., (2017) stated that cleft palate patients are known to suffer adversely on social scene in terms of communication and positive interaction with others. They experience difficulties participating in social activities due to low self-esteem and most people may perceive them socially unacceptable resulting to social ostracism (Bull & Rumsey, 1988). Nevertheless, Rieger et al., (2006) found that majority of patients with repaired cleft palate maintain a positive environment in forming new positive relations.

4.3.6 Exclusion from social gatherings

The researcher sought to investigate the effects of VPI on social gatherings of the respondents. Figure 4.7 illustrates the respondents' views on social gatherings involvement.

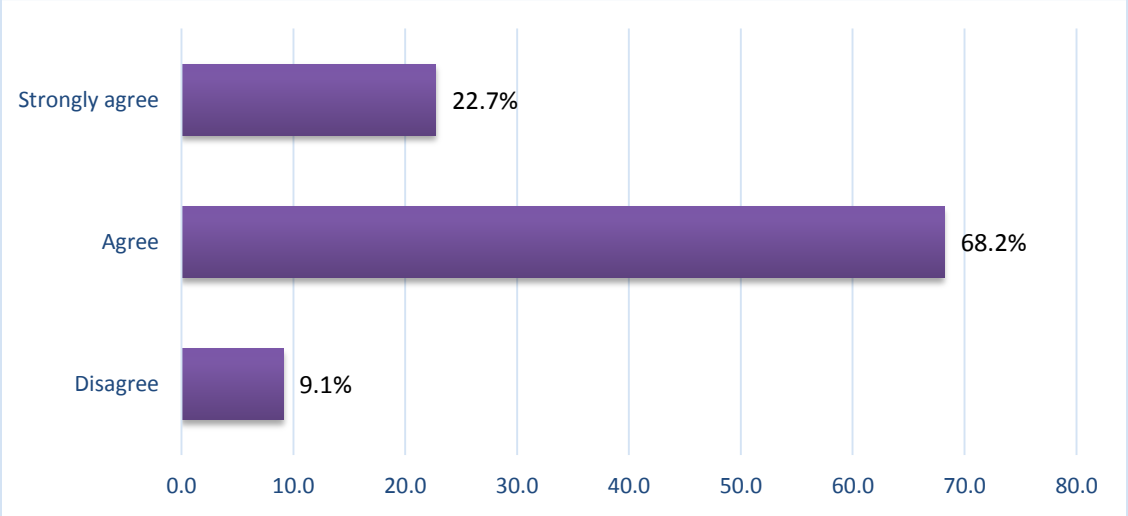

Figure 4.7: Respondents statement on whether they exclude themselves from social gatherings

More than half, (12) of the respondents agreed that they exclude themselves from social gatherings, with only 2 respondents who disagreed with the statement as shown in Figure 4.7. This concurs, with a study done by, Sousa, Devare, and Ghansani (2009), on social

stigma and cleft disorders, which revealed that those with cleft palate are discriminated negatively by being labeled different from others. Part of life of these individuals is teasing which causes unhappiness due to the incapacity to communicate, and this makes them socially recluse (Bhuskute et al, 2017).

4.3.7 Association between VPI severity and Social interaction

The study further sought to establish the association of severity of VPI and social interaction. The findings are illustrated in Table 4.4

Table 4.4 Association between VPI severity and Social interaction

		VPI severity			Chi - square	P-value
		Mild	**Moderate**	**Severe**		
I have challenges in making friends	Disagree	1 (50%)	0	1 (50%)		
	Agree	1 (7.7%)	6 (46.2%)	6 (46.2%)	4.972	0.29
	Strongly agree	1 (14.3%)	1 (14.3%)	5 (71.4%)		
I do not find social interaction enjoyable	Agree	1 (7.1%)	5 (35.7%)	8 (57.1%)		
	Strongly agree	2 (25%)	2 (25%)	4 (50%)	1.422	0.491
I have difficulties in initiating positive interaction with their peers	Disagree	1 (33.3%)	1 (33.3%)	1 (33.3%)		
	Agree	2 (14.3%)	6 (42.9%)	6 (42.9%)	6.161	0.042
	Strongly agree	0	0	5 (100%)		
I exclude myself from social gatherings	Disagree	1 (50%)	1 (50%)	0		
	Agree	1(6.7%)	5(33.3%)	9(60%)	4.26	0.372
	Strongly agree	1 (20%)	1(20%)	3(60%)		
I like to have friends but am unable to make some friends	Disagree	1(50%)	1(50%)	0		
	Agree	1 (11.1%)	3(33.3%)	5(55.6%)	3.693	0.449
	Strongly agree	1 (9.1%)	3 (27.3%)	7 (63.6%)		

As shown in Table 4.4, there was significant association between social interaction in difficulties initiating positive interactions with their peers and VPI ($p = 0.042$, $p<0.05$). This finding shows that an increase in VPI severity is likely to increase respondents' difficulties in initiating positive interaction with their peers. However, there was no statistically significant association between VPI severity and challenges in making friends ($p =0.29$, $p>0.05$), finding social interaction enjoyable ($p =0.491$, $p>0.05$), and self-exclusion from social gathering ($p =0.372$, $p>0.05$). Initiating positive interactions within a social context requires improved level of self-confidence and self-awareness where other negative perception from others cannot have a detrimental influence on the level of individual wellbeing (Ndungu & Kinyua, 2009).

Similar findings were reported by Hunt et al (2005) whose study revealed that cleft palate patients had differences in the level of comfort that other people showed when meeting or mixing with others. Such experiences were generally more positive in adulthood than in childhood or during the teenage years. A common view expressed by the adults was that their self-confidence increased with age. Improvements in self-confidence were associated with support and guidance from family and friends, support from speech and language therapists, psychologists and counselors. However, Ha et al. (2015) did not find any significant difference between severity of VPI and forming social interaction among patients with repaired cleft palate. Leu et al. (2021) found that social interaction among patients with cleft palate is not dependent on the severity of VPI. The difference in findings can be attributed to majority of the respondents being of almost similar level of severity.

4.4 Effect of VPI on functional ability of patients with repaired palate

The second objective sought to investigate the effect of VPI on functional ability of patients where five key aspects were investigated. They include talking, swallowing, speech, perception by others and social impact of the respondents.

4.4.1 Talking problems

The study sought to establish talking challenges experienced by respondents.

The table below illustrates the findings.

Table 4.5 Respondent's ability in talking

	Almost n (%)	**Sometimes n (%)**	**Often n (%)**	**Always n (%)**
Air comes out of nose when I talk		4(18.2%)	5(22.7%)	13(59.1%)
I run out of breath when I talk	1(4.5%)	4(18.2%)	4(18.2%)	13(59.1%)
It is hard talking in long sentences	2(9.1%)	4(18.2%)	3(13.6%)	13(59.1%)
My speech is too weak	2(9.1%)	4(18.2%)	6(27.3%)	10 (45.5%)
I have trouble being understood when I'm in a hurry	2(9.1%)	2(9.1%)	9(40.9%)	9 (40.5%)
My speech gets worse toward the end of the day	3(13.6%)	6 (27.3%)	11(50%)	2 (9.1%)
My speech sounds different than other people	1(4.5%)	2 (9.1%)	4(18.2%)	15(68.2%)

Functional ability of the respondents while talking was analyzed, out of the 22 respondents, 13 of them asserted that air comes out of the nose when they talk, 13 of the respondents also run out breath when they talk, 10 of the respondents affirmed that their speech is always weak while 9 often have trouble being understood when in a hurry. Half of the respondents also asserted that often, their speech gets worse toward the end of the day and 15 stated that their speech sounds different from that of other people. The results also showed that there was a link between VPI and functional ability in talking. The findings concur with the existing literature which had shown that despite cleft palate repair, the wellbeing of the patients tends to reduce with time (Rhodes, 2009).

4.4.2 The association between VPI severity and challenges when talking

The study also sought to establish the association between VPI severity and challenges when talking among the respondents as illustrated in Table 4.6.

Table 4.6 The association between VPI severity and challenges when talking

		VPI severity				
		Mild	**Moderate**	**Severe**	**Chi square**	**P-value**
Air comes out of nose when I talk	Sometimes	2 (50%)	2 (50%)	0		
	Often	1 (25%)	2 (37.5%)	2 (37.5%)	10.202	0.037
	Always	0	0	10(76.9%)		
My speech sounds different than other people	Almost	0	1 (100%)	0		
	Sometimes	2 (100%)	0	0		
	Often	1 (25%)	2 (50%)	1 (25%)	19.385	0.004
	Always	0	4 (26.7%)	11 (73.3%)		

The findings showed that there was a statistically significant association between VPI severity and air coming out of the nose when the respondents talk ($p = 0.037$, $p < 0.05$) and assertion that their speech was different from others ($p = 0.004$, $p < 0.05$). The findings concur with Biavati (2012) who stressed that structural defects correction through surgery scarcely changes that functioning since articulation problem remains even after surgery.

4.4.3 Swallowing problems

The researcher sought to establish swallowing problems from the respondents as illustrated below.

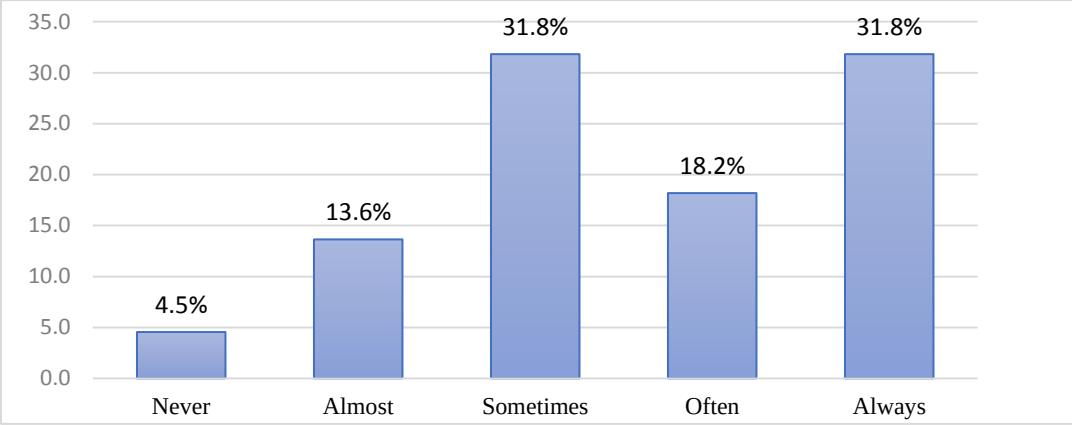

Figure 4.8 Respondents frequency of fluid coming out through the nose while drinking

Figure 4.8 illustrates that out of 22 respondents, 7 always had liquids coming out of their noses when they drink while only 1 of the respondents did not have liquids coming out of his nose when drinking despite undergoing cleft palate repair surgery. This shows that cleft palate repair surgery does not always have perfect outcomes among individual with cleft palate. The findings from the study are like those from a study conducted in Nigeria which highlighted that the success of cleft palate repair surgery was approximately 70%

according to Abdurrazaq et al. (2013). Additionally, Zhang et al. (2017) also stressed that cleft palate surgery is associated with significant complications and recurrence of the previous condition with time. The recurrence of the condition even after surgery present a stronger emphasis on better aspects which help in maintaining improved focus on management of the condition.

4.4.4 Feeding Issues

Additionally, the researcher sought to find out from the respondents the frequency of food coming out through the nose while eating. The results are presented in Figure 4.9 below.

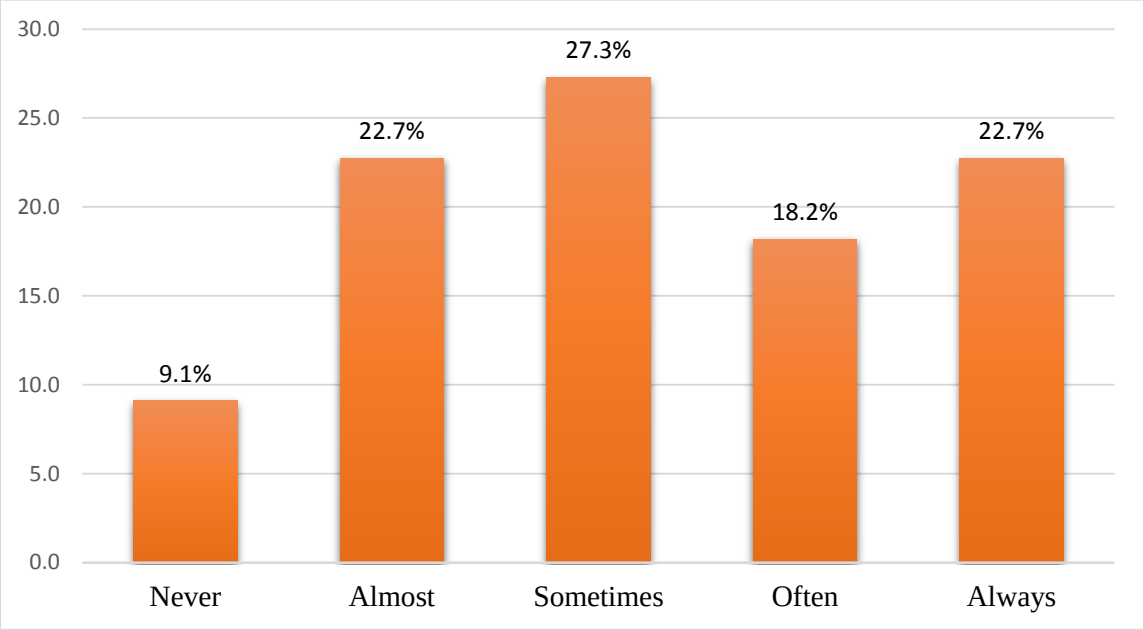

Figure 4.9 Respondents frequency of food coming out through the nose while eating

As presented in figure 4.9 above, six of the respondents affirmed that sometimes food comes out of their nose while eating. The surgery performed is supposed to help in improving this condition. However, even after the cleft palate surgery, a significant

number of individuals still face many challenges including food coming out of their noses. This could be attributed to the severity of VPI as well as the duration since the surgery was conducted.

4.4.5 Perception by others

The study also sought to investigate the perception people have on persons with VPI after a cleft repair. The results are represented in figure 4.10

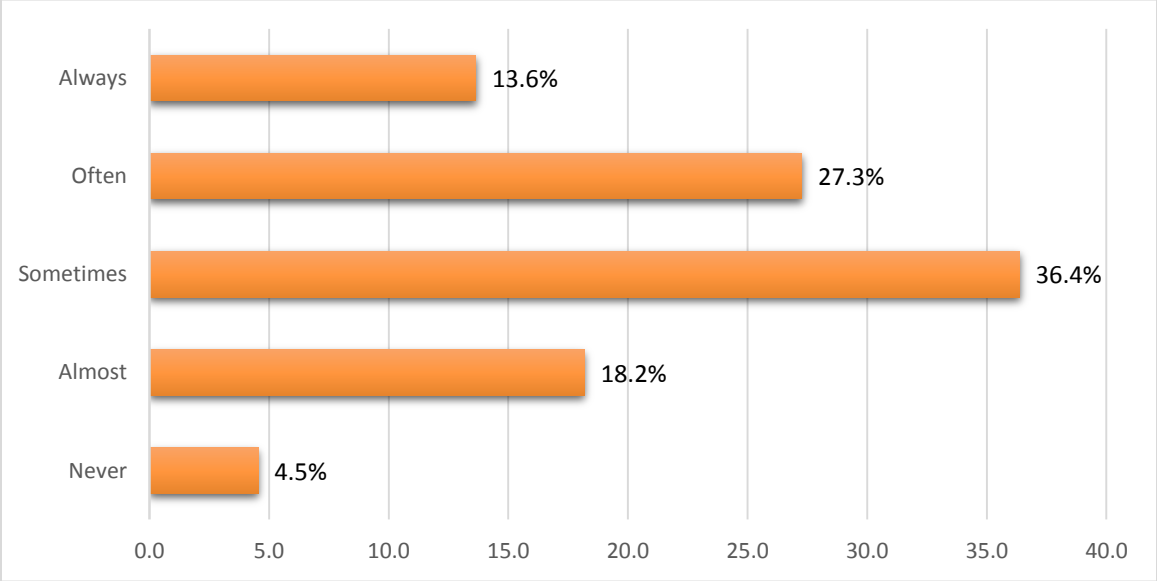

Figure 4.10 Respondents assertion on whether others make fun of them when food or drinks comes out through the nose

In figure 4.10 above, 36% of the respondents sometimes felt that others make fun of them when food or drink comes out of their nose. The perception that is maintained in the society is based on the level of interaction and individual self-efficacy and confidence in everything they do. Cleft palate patients have lower self-esteem which influences individual perception. This agrees with Beluci and Genaro, (2016) findings on quality of

life among cleft palate patients which was ranging from low to moderate and highly influenced by how others perceive them.

4.4.6 Association between VPI severity and swallowing problems among respondents

The study, similarly, sought to determine the association between VPI severity and swallowing problems among respondents. The results are presented in table 4.7

Table 4.7 Association between VPI severity and swallowing challenges among respondents

		VPI severity			Chi-Square	P-value
		Mild	Moderate	Severe		
Liquids comes out of my nose while drinking	Never	0	1(100%)	0		
		0.0%	100.0%	0.0%		
	Almost	1 (33.3%)	0	2(66.7%)		
	Sometimes	1 (14.3%)	4(57.1%)	2 (28.6%)	9.641	0.291
	Often	1 (25%)	1 (25%)	2 (50%)		
	Always	0	1 (14.3%)	6 (85.7%)		
Food comes out of my nose while eating	Never	0	2 (100%)	0		
	Almost	1(20%)	2(40%)	2(40%)		
	Sometimes	2 (33.3%)	1(16.7%)	3 (50%)	9.302	0.317
	Often	0	1 (25%)	3 (75%)		
	Always	0	1 (20%)	4 (80%)		

Table 4.7 presents chi-square test results for association between VPI severity and swallowing challenges among respondents.

The result show no statistically significant association between severity of VPI and liquids coming out of the nose while drinking among the respondents at x^2 (8) = 9.641, p =0.291, p>0.05. This, therefore, implies that the severity of VPI does not influence the frequency of liquids coming out of the noses of patients who undergone cleft palate repairs. The analysis further showed no statistically significant association between VPI severity and frequency of food coming out through the nose, x^2 (8) = 9.302, p =0.317, p>0.05. Thus the severity of VPI does not influence the frequency of food coming out through the nose of patients who underwent cleft palate repair. The results contradict several past studies which found a higher influence of VPI severity in functional ability – swallowing. The difference could be attributed to small sample size included in the study. Moon and Kuehn (2015) explained that the correction of cleft palate condition is based on the timing when it is recognized, and surgery performed mainly before the school going age to enhance student performance.

4.4.7 Speech limitations

Speech limitations experienced by the respondents were also investigated. The results are presented in Table 4.8

Table 4.8 Respondents speech limitations

	Almost n (%)	**Sometimes n (%)**	**Often n (%)**	**Always n (%)**
My speech is hard for strangers to understand	1 (4.5%)	3(13.6%)	6(27.3%)	12(54.5%)
My speech is hard for friends to understand		6(27.3%)	9(40.9%)	7(31.8%)
My speech is hard for family to understand	4(18.2%)	12(54.5%)	2(9.1%)	4(18.2%)
I have trouble being understood when others can't see my face, for example, in a car		3(13.6%)	11(50%)	8(36.4%)
I have trouble being understood on the phone		2(9.1%)	6(27.3%)	14(63.6%)

As illustrated in table 4.8 above, out of the 22 respondents 12 mentioned that, the speech is always hard for strangers to understand, 9 asserted that they often find it difficult to express themselves in a way their friends can understand their speech, 12 of the respondents also felt that their speech was hard for their family members to understand. Other half of the respondents also stressed that it was difficult for others to understand them when not having a face to face communication. Based on the findings of the study, cleft palate surgery is therefore associated with major challenges especially in relation to speech. The findings are consistent with Rhodes (2009) who found that cleft palate patients have trouble with their speech and other common manifestation such as hyper nasality, decreased vocal intensity, short phrases and nasal emission even after surgery. Lohmander-Agerskov (1998) study on speech outcomes after cleft palate surgery also

showed that 8% of children had low prevalence of hypernasality after cleft palate closure and pharyngeal flap surgery. The speech problems that were identified among the children investigated were associated with retracted oral articulation of alveo-dental pressure plosives. Biavati, (2017) also found that, structural defects correction through surgery in the velopharyngeal port scarcely changes the functioning by default, as articulation may still endure after surgery.

4.4.8 The association between VPI severity and speech limitations

The researcher further sought to establish the association between severity of VPI and speech limitation among the respondents as shown in Table 4.9.

Table 4.9 The association between VPI severity and speech ability

		VPI severity			Chi-square	P-value
		Mild	Moderate	Severe		
My speech is hard for strangers to understand	Almost	0	1 (100%)	0		
	Sometimes	1 (33.3%)	2 (66.7%)	0	12.31	0.023
	Often	2 (33.3%)	2 (33.3%)	2 (33.3%)		
	Always	0	2 (16.7%)	10 (83.3%)		
I have trouble being understood when others can't see my face.	Sometimes	1 (33.3%)	2 (66.7%)	0		
	Often	2 (18.2%)	4 (36.4%)	5 (45.5%)	7.662	0.042
	Always	0	1 (12.5%)	7 (87.5%)		

The results from table 4.9 show significant association between VPI severity and difficulty for strangers to understand their speech (p = 0l023, p<0.05) as well as VPI

severity and trouble to understand others when they cannot see their face. This means that higher VPI severity is likely to increase the difficulty of being understood when others cannot see their face. These findings are similar to Bhuskute et al. (2017) who found that the VPI score was highly associated with improved speech after surgery where it was determined that high scores were associated improved speech after surgery. Thus, as revealed in this study, mild VPI is less associated with difficulties in speech when talking to strangers as well as having trouble when others cannot see their face.

4.5 Level of accessibility/availability of speech therapy and counseling services for patients with repaired palate

Interviews were conducted to establish the availability of speech therapy and counseling services for patients with repaired palate. Two surgeons were interviewed separately tape recorded and transcribed iteratively to develop themes. Two themes were identified which included services available for patients, and challenges in accessing speech therapy services. Responses were coded S1 and S2.

4.5.1 Services available for patients

The participants highlighted that speech therapy was the only service to patients for improvement of their quality life after cleft repair. S1…. stated that

> "*the hospital despite being the biggest referral hospital in the country has been unable to fully manage the needs of individuals with cleft palate repair despite the increasing prevalence*."

S2…stated that,

"*the hospital management has the mandate to acknowledge this challenge and incorporate more services to help empower and improve the performance levels of patients who have undergone cleft repair*." S1 & S2…. asserted that,

> "s*peech therapy is the most important service required by patients after cleft palate repair.*

These findings are echoed in a study by Murthy (2009) who concluded the access to care is very minimal in developing countries where there is minimal information on the cleft palate treatment. The minimal services available for patients make it difficult to ensure continuous monitoring of the condition.

4.5.2 Challenges in accessing speech therapy services

The major challenge that has been identified is that there are very few speech therapists in the country despite increasing number of individuals with cleft palate. This means that very few patients can get the attention of highly qualified speech therapists. S1…. stated that,

> "*few speech therapists complicate the management of cleft palate considering that those who have undergone cleft repair are unable to learn speech effectively, due to few or no available speech therapist"*

S2…. highlighted that,

"*generally, there are few speech therapists in the country making it difficult to get quality services leading to inability to improve speech among individuals with this condition*." Murthy (2009) present a focus on key challenges to treatment which include developing a different intervention approach to older patients because they are greatly influenced by

financial, logistical factors and demands in their life in planning for treatment. Inadequate number of therapists makes it difficult to attain a team-based approach to treatment of individuals with Cleft palate in developing countries. The speech-language services are also limited or not available at all in developing countries making it difficult to improve the lives of cleft palate patients (Sell, 2007; Gopalakrishna & Agarwal, 2010).

4.6 The role of speech therapy on communication patients with of a repaired palate

The research also sought to establish the role of speech therapy on the communication of patients with the repaired palate. An interview was conducted with one speech therapist at Kenyatta National Hospital. The focus was on approaches speech therapists use in the management of VPI, procedures used by speech therapists in the management of VPI, challenges faced by speech therapists in the management of VPI and recommended methods in the management of VPI.

4.6.1 Approaches speech therapists use in the management of VPI

The interview included an assessment of the different methods that the interviewee (Speech therapist) uses in the management of VPI. The respondent stated that"

> *"the method that I normally use is listening and judgment of the symptoms. There is less emphasis on speech therapy within the hospital, which preset a difficult commitment to improving different patient needs."*

The findings are consistent with Kuehn and Henne (2003) who found that most hospitals do not have essential interventions in the management of VPI because of a lack of emphasis on speech therapy concerns within society. Leuchter et al. (2010) also affirmed

that the inability of consideration of speech therapy as a significant intervention to patients with speech problems limit the overall commitment in healthcare to outline diverse management methods.

4.6.2 Procedures used by speech Therapists in management of VPI

The interviewee was asked about the available procedures that are used to improve speech among patients with the repaired palate. The respondent asserted that,

> "*the hospital only recognizes speech therapy as a key procedure in the treatment of VPI.*"

The respondent further stressed that,

> "*the application of other procedures has not been considered in the hospital hence not applicable*."

Saman and Tatum (2012) also found out that speech therapy is the most used VPI treatment method in low resource settings because it is faster and comfortable to engage patients based on the interactive environment developed between speech therapists and patients.

4.6.3 Challenges faced by Speech Therapists in the management of VPI

The respondent was also asked about the challenges they encounter in the rehabilitation of speech in patients with VPI. Few speech therapists and strain to offer services were the challenges that were identified. The respondent stressed that

"*the main challenge is that the number of patients seeking care has been increasing while we are very few who are offering speech therapy leading to high workload*."

The findings in this study conquer with Thanawirattananit and Thanaviratananich (2013), who highlighted that there are few speech therapists globally despite the increasing patients seeking services.

However, the respondent suggested that,

"*speech therapy should be part and parcel in the management of VPI since most patients prefer surgical repair without seeking speech therapy services*."

The respondent also stressed that the,

"*training and employment of more speech therapists would help in easing the current pressure experienced*."

These findings are in line with Kuehn and Henne (2003) who suggested increasing the number of speech therapists as well as adopting other methods such as articulation therapy to improve the quality of care and management of VPI among patients with cleft palate.

CHAPTER FIVE

SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter presents the summary of the findings, conclusion and recommendations from the study findings and areas of further research.

5.2 Summary of the Research findings

The purpose of the study was to evaluate the effects of VPI on the quality of life of adults with repaired cleft palate at Kenyatta National Hospital. The summary of the research findings was based on the study objectives as follows.

5.2.1. The effect of VPI on the social interaction of patients with repaired cleft palate

Firstly, social interactions are essential in building individual confidence. The results from this study, however, have revealed a lower level of social interaction among respondents. Despite the understanding that social gatherings are enjoyable, few cleft palate repair persons with VPI are willing to participate. Most of these individuals have challenges in forming positive relationships. Most of the respondents highlighted that they have difficulties in initiating relationships, which is explained by sole self-confidence and commitment to improving outcomes. Positive interactions are developed based on respect and self-awareness among respondents.

5.2.2. The effect of VPI on the functional ability of patients with a repaired palate

Secondly, this study established that respondents with VPI after cleft palate repair have challenges in their functionality, especially, speech, swallowing, and how others perceive

them regarding their functional abilities. The study also found that most of the persons with VPI after cleft palate repair had challenges of air coming out of the nose and speech difficulties. When compared to others, the respondents experienced significant functional challenges that also included difficulties in swallowing, although these challenges did not have a higher influence on their wellbeing. The speech challenges identified include difficulty for strangers to understand their speech when talking to them without seeing their faces.

5.2.3 The level of accessibility/availability of speech therapy and counseling services for patients with a repaired palate

Thirdly, the results of the study indicated that, availability of speech therapy and counseling services for patients has been a significant challenge among patients with the repaired palate. The hospital, despite being the biggest referral hospital in the country, KNH has been unable to address the speech therapy challenge. The major problem that has been identified is that there are very few speech therapists in the country despite an increasing number of individuals with cleft palate. It is essential to address the challenges of individuals having VPI after cleft palate repair because they suffer from low confidence, lack courage, and are unable to develop relations.

5.2.4 The Role of Speech Therapy on communication of patients with repaired cleft palate

The results of the study found that, a method used in assessment of VPI is listening judgment. The Hospital recognizes speech therapy as a key procedure in treatment of VPI. The main challenge is that the number of patients seeking care has been increasing

while there are very few who are offering speech therapy leading to high workload. The study also asserted the importance of involving speech therapists in the management of patients with cleft palate, before and after repair. The study further recommends training and employment of more speech therapists.

5.3 Conclusion

This study has resulted in four main conclusions based on the objectives.

Firstly, based on the findings of many adults with repaired cleft palate had challenge with social interactions. They did not find social interactions enjoyable because of difficulty to communicate effectively with their peers. It was also revealed that, they had challenges in making new friends, were often teased and this rendered to low self-confidence hence unsuccessful positive interaction and exclusion from social gatherings. The study concluded that there was a significant association between VPI severity and social interaction.

Secondly, this study revealed that functional ability of most adults with repaired cleft palate was affected by VPI. According to the study findings, higher VPI severity is likely to increase difficulty of being understood when others cannot see their face. However, the study found out that, VPI severity does not influence functional ability in swallowing.

Thirdly, according to findings on the level of accessibility of speech therapy services, it is logical to conclude that, speech therapy is the most important service required by patients after cleft palate repair; however, there are minimal services available for cleft palate treatment, and very few speech therapists in the country.

The study established that there was less emphasis on speech therapy services. The biggest challenge revealed is the increasing number of patients seeking services, from very few professionals offering speech therapy services.

5.4 Recommendations

The study recommends the following based on the findings.

i. Training and counseling sessions for patients with cleft palate repair so that they can embrace their condition and focus on improving their personal growth. The training sessions should also focus on self-confidence and avoid being influenced by what others say about their conditions.

ii. Patients with VPI after cleft palate repair should also be encouraged to form relationships that are essential in controlling their high level of solitary life so that these patients lead within their social context.

iii. Health education of patients with cleft palate on importance of follow up after repair due to the recurrence of the condition after repair.

iv. Hospitals should consider adopting speech therapy as a significant healthcare delivery section that will emphasize on improving the wellbeing of patients who need speech therapy.

v. Speech therapist should be involved in the management of cleft palate patients before and after repair.

vi. The government should create awareness regarding the need to promote speech therapy courses and medical education to increase the number of available speech therapists.

5.4.1 Policy Recommendations

i. The study recommends the various stakeholders in the Ministry of Health to provide a framework to deal with cleft palate and adopt better treatment strategies for persons who have undergone cleft palate repair.

ii. The study recommends the multidisciplinary team, i.e., maxillofacial surgeons, plastic surgeons, orthodontists, in understanding the quality of life for patients undergoing treatment at the facility, hence creation of better protocols in management of these patients.

5.4.2 Suggestions for Further Research

Study findings are useful for those interested in pursuing this area on the quality of life for such patients by serving as a reference point. Therefore, the study suggests for further research focusing on the quality of life of adults with repaired cleft palate.

REFERENCES

Abbasi, M. H., Habib, H., & Bhatti, Y. A. (2013). Genetical basis of cleft lip & palate: A review. In *Pakistan Journal of Medical and Health Sciences*.

Abdurrazaq, T. O., Micheal, A. O., Lanre, A. W., Olugbenga, O. M., & Akin, L. L. (2013). Surgical outcome and complications following cleft lip and palate repair in a teaching hospital in Nigeria. *African Journal of Paediatric Surgery*. https://doi.org/10.4103/0189-6725.125447

Adetayo, O., Ford, R., & Martin, M. (2012). Africa has unique and urgent barriers to cleft care: Lessons from practitioners at the pan-african congress on cleft lip and palate. *Pan African Medical Journal*. https://doi.org/10.11604/pamj.2012.12.15.1638

Agrawal, K. & Gopalakrishna, A. (2010). Cleft palate repair and variations. *Indian Journal of Plastic Surgery*, *42*(S 01), S102-S109.

Alighieri, C., Bettens, K., Bruneel, L., D'haeseleer, E., Van Gaever, E., & Van Lierde, K. (2020). Effectiveness of speech intervention in patients with a cleft palate: Comparison of motor-phonetic versus linguistic-phonological speech approaches. *Journal of Speech, Language, and Hearing Research*. https://doi.org/10.1044/2020_JSLHR-20-00129

American Speech-Language-Hearing Association (2012). Summary of Changes to Standards for Accreditation of Graduate Education Programs in Audiology and Speech-Language Pathology. Retrieved December 1, 2015 from http://www.asha.org/uploadedFiles/ January-2013-Changes-Accreditation-Standards.pdf#search=%22graduate%22

Amick, L. J., Chang, S. E., Wade, J., & McAuley, J. D. (2017). Social and cognitive impressions of adults who do and do not stutter based on listeners' perceptions of read-speech samples. *Frontiers in Psychology*. https://doi.org/10.3389/fpsyg.2017.01148

Angulo-Castro, E., Acosta-Alfaro, L. F., Guadron-Llanos, A. M., Canizalez-Román, A., Gonzalez-Ibarra, F., Osuna-Ramírez, I., & Murillo-Llanes, J. (2017). Maternal risk factors associated with the development of cleft lip and cleft palate in

Mexico: A case-control study. *Iranian Journal of Otorhinolaryngology*. https://doi.org/10.22038/ijorl.2017.19302.1650

Ary, D., Jacobs, L. C., & Sorensen, C. K. & Walker, A. (2014). Introduction to research in education. Massachusetts: Wadsworth Cengage Learning.

Baigorri, M., Crowley, C., & Sommer, C. (2020). Addressing the Gap in Education for Cleft Palate: A Module Training Series for Craniofacial Assessment and Treatment. *Perspectives of the ASHA Special Interest Groups*. https://doi.org/10.1044/2020_persp-19-00138

Bessell, A., Sell, D., Whiting, P., Roulstone, S., Albery, L., Persson, M., Verhoeven, A., Burke, M., & Ness, A. R. (2013). Speech and language therapy interventions for children with cleft palate: A systematic review. In *Cleft Palate-Craniofacial Journal*. https://doi.org/10.1597/11-202

Bhuskute, A., Skirko, J. R., Roth, C., Bayoumi, A., Durbin-Johnson, B., & Tollefson, T. T. (2017). Association of velopharyngeal insufficiency with quality of life and patient-reported outcomes after speech surgery. *JAMA Facial Plastic Surgery*. https://doi.org/10.1001/jamafacial.2017.0639

Botticelli, S., Küseler, A., Mølsted, K., Ovsenik, M., Nørholt, S. E., Dalstra, M., Cattaneo, P. M., & Pedersen, T. K. (2019). Palatal morphology in unilateral cleft lip and palate patients: Association with infant cleft dimensions and timing of hard palate repair. *Orthodontics and Craniofacial Research*. https://doi.org/10.1111/ocr.12318

Cashin-Gurbutt, (2018). Profile of Cleft Lip and Cleft Palate at a Public Hospital in Southern India. *Indian pediatrics*, *56*(9), 753-755.

Chapman, K. E., Black, J. D., Girotto, J. A., & Oppenheimer, A. J. (2009). When my child was born: cross-cultural reactions to the birth of a child with cleft lip and/or palate. *The Cleft palate-craniofacial journal*, *46*(5), 545-548.

Cleft Palate Foundation (2011). Available at *http//www.cleft.com* Date of access: 13 July 2018

Conversion Academic (2018). Cleft lip and/or palate: one organization's experience with more than a quarter million surgeries during the past decade. *Journal of Craniofacial Surgery*, *25*(5), 1601-1609.

Cooper, D. R. & Schindler, P. S. (2011). *Business Research Methods*, 142-155.

Costa, B., White, P., & Stock, N. M. (2020). Satisfaction With Health Care in Families Following a Diagnosis of Cleft Lip and/or Palate in the United Kingdom. *Cleft Palate-Craniofacial Journal*. https://doi.org/10.1177/1055665619888318

Creswell, J. W. (2003). Research design: Qualitative and mixed method approaches Disorders. *Disability Studies Quarterly*, *29*: 4.

Cronin, A., McLeod, S., & Verdon, S. (2020). Holistic communication assessment for young children with cleft palate using the international classification of functioning, disability and health: Children and youth. *Language, Speech, and Hearing Services in Schools*. https://doi.org/10.1044/2020_LSHSS-19-00122

Csikszentmihalyi, M., & Larson, R. (2014). Validity and reliability of the experience-sampling method. In *Flow and the Foundations of Positive Psychology: The Collected Works of Mihaly Csikszentmihalyi*. https://doi.org/10.1007/978-94-017-9088-8_3

Cubitt, J. J., Hodges, A. M., Van Lierde, K. M., & Swan, M. C. (2014). Global variation in cleft palate repairs: An analysis of 352,191 primary cleft repairs in low- to higher-middle-income countries. *Cleft Palate-Craniofacial Journal*. https://doi.org/10.1597/12-270

D'Antonio, L. L., & Nagarajan, R. (2003). Use of a consensus building approach to plan speech services for children with cleft palate in India. *Folia phoniatrica et logopaedica*, *55*(6), 306-313

Desu, M. M. (2012). *Sample size methodology*. Elsevier.

Edmondson, R., & Reinbartsen, D (1998). The young child with cleft lip and palate: Intervention needs in the first three years. Infants and Young Individuals, 11(2), 12-20. Hamlen M. Speech changes after pharyngeal flap surgery. *Plastic Reconstruction Surg*.1970; 46:437– 444.

Ellen, S. (2018). Slovin's Formula Sampling Techniques. In *Sciencing*.

Feragen, K. B., Særvold, T. K., Aukner, R., & Stock, N. M. (2017). Speech, language, and reading in 10-year-olds with cleft: Associations with teasing, satisfaction with speech, and psychological adjustment. *Cleft Palate-Craniofacial Journal*. https://doi.org/10.1597/14-242

Fritzsche, S. (2019). Care of the Asian American Child With Cleft Lip or Palate. In *Plastic Surgical Nursing*. https://doi.org/10.1097/PSN.0000000000000258

Fuangtharnthip, P., Chonnapasatid, W., Thiradilok, S., Manopatanakul, S., & Jaruratanasirikul, S. (2021). Registry-Based Study of Prevalence of Cleft Lip/Palate in Thailand from 2012 to 2015. *Cleft Palate-Craniofacial Journal*. https://doi.org/10.1177/1055665620987677

Gama, A. P. M., & Alves, C. A. (2021). Research Methodology. In *Accounting, Finance, Sustainability, Governance and Fraud*. https://doi.org/10.1007/978-981-33-4846-2_5

Gandhi, J., Seyam, O., Liang, R., Smith, N. L., & Khan, S. A. (2020). Psychosocial and Sexual Implications of Repaired Cleft Lip in an Adult Male. *Cureus*. https://doi.org/10.7759/cureus.8563

Gay, R. V. (2016). Some practical guidelines for effective sample size determination. *The American Statistician, 55*(3), 187-193.

Govathi, K N, Hari P. A Study on Patterns of Compensatory Articulation Errors with Reference to Age of Surgery in Children with Repaired Cleft Lip and Palate. Glob J Oto 2017; 7(2): 555706. DOI: 10.19080/GJO.2017.07.555706. 005 Global *Journal of Otolaryngology.*

Ha, S., Koh, K. S., Moon, H., Jung, S., & Oh, T. S. (2015). Clinical outcomes of primary palatal surgery in children with nonsyndromic cleft palate with and without lip. *BioMed Research International*. https://doi.org/10.1155/2015/185459

Hameed, T. (2016). Sampling methods in research methodology: How to choose a sampling technique. *International Journal of Academic Research in Management (IJARM).*

Hardin, C. D., & Higgins, E. T. (1996). Shared reality: How social verification makes the subjective objective. In *Handbook of Motivation and Cognition: The Interpersonal Context*.

Heale, R., & Twycross, A. (2015). Validity and reliability in quantitative studies. *Evidence Based Nursing*. https://doi.org/10.1136/eb-2015-102129

Helal, N., Ford, M., Basri, O., Schuster, L., Martin, B., & Losee, J. (2020). Relationship of Velopharyngeal Insufficiency With Face Mask Therapy in Patients With Cleft Lip and Palate. *Cleft Palate-Craniofacial Journal*. https://doi.org/10.1177/1055665619865155

Hopper, R. A., Tse, R., Smartt, J., Swanson, J., & Kinter, S. (2014). Cleft palate repair and velopharyngeal dysfunction. *Plastic and Reconstructive Surgery*. https://doi.org/10.1097/PRS.0000000000000184

Howard, S., & Lohmander, A. (2013). Cleft Palate Speech: Assessment and Intervention. In *Cleft Palate Speech: Assessment and Intervention*. https://doi.org/10.1002/9781118785065
https://doi.org/10.26452/ijrps.v11iSPL3.3407

Hunt, O., Burden, D., Hepper, P., & Johnston, C. (2005). The psychosocial effects of cleft lip and palate: a systematic review. *European journal of orthodontics, 27(3)*, 274-285.

Jackson, I. T., Moreira-Gonzalez, A. A., Rogers, A., & Beal, B. J. (2004). The buccal flap—a useful technique in cleft palate repair?. *The Cleft palate-craniofacial journal*, *41*(2), 144-151.

Johanisson, E. B., Lohmander, P. & Persson,H. 2014). Current surgical practices in cleft care: cleft palate repair techniques and postoperative care. *Plastic and reconstructive surgery*, *124*(3), 899-906.

Jones, C. E., (2003). Speech development of children with cleft palate before and after palatal surgery. *The Cleft palate-craniofacial journal*, *40*(1), 19-31.

Källén, B. (2014). Orofacial Clefts. In *Epidemiology of Human Congenital Malformations* (pp. 73-77). Springer, Cham.

Kara, M., Calis, M., Kara, I., Incebay, O., Kulak Kayikci, M. E., Gunaydin, R. O., & Ozgur, F. (2020). Does early cleft palate repair make difference? Comparative evaluation of the speech outcomes using objective parameters. *Journal of Cranio-Maxillofacial Surgery*. https://doi.org/10.1016/j.jcms.2020.09.003

Kinter, S. (2018). Clinical Evaluation of Velopharyngeal Insufficiency–Specific Quality of Life: Expanding the Standard of Care. *Perspectives of the ASHA Special Interest Groups*. https://doi.org/10.1044/persp3.sig5.64

Kosowski, T., Weathers, W., Wolfswinkel, E., & Ridgway, E. (2012). Cleft palate. *Seminars in Plastic Surgery*. https://doi.org/10.1055/s-0033-1333883

Kristin. (2017). Speech, Language, and/or Reading: Associations with Teasing, Satisfaction with Speech, and Psychological Adjustment. *The Cleft Palate Craniofacial Journal*

Kuehn, D. P., & Moller, K. T. (2000). Speech and language issues in the cleft palate population: The state of the art. The Cleft Palate-Craniofacial Journal,37(4), 348-348

Kuehn, D. P., Moon, J. B., & Folkins, J. W. (2010). Levator veli palatini muscle activity in relation to intranasal air pressure variation. The Cleft Palate-Craniofacial Journal, 30(4), 361–368.

Kummer, A. W. (2013). Speech therapy for errors secondary to cleft palate and velopharyngeal dysfunction. *Seminars in Speech and Language*. https://doi.org/10.1055/s-0031-1277721

Lee, J., Ku, B., Combs, P. D., Da Silveira, A. C., & Markey, M. K. (2017). Quantitative Anthropometric Measures of Facial Appearance of Healthy Hispanic/Latino White Children: Establishing Reference Data for Care of Cleft Lip With or Without Cleft Palate. *3D Research*. https://doi.org/10.1007/s13319-017-0128-9

Leonard, B. J., Brust, J. D., Abrahams, G., & Sielaff, B. (1991). Self-concept of children and adolescents with cleft lip and/or palate. *The Cleft Palate-Craniofacial Journal*, *28*(4), 347-353.

Leu, G. R., Ebert, B. E., Roby, B. B., & Scott, A. R. (2021). Cleft Palate Repair by Otolaryngologist-Head and Neck Surgeons: Risk Factors for Postoperative Fistula. *Laryngoscope*. https://doi.org/10.1002/lary.29191

Leuchter, I., Schweizer, V., Hohlfeld, J., & Pasche, P. (2010). Treatment of velopharyngeal insufficiency by autologous fat injection. *European Archives of Oto-Rhino-Laryngology*, 267(6), 977-983.

Lohmander-Agerskov, A. (1998). Speech Outcome after Cleft Palate Surgery with the G teborg Regimen Including Delayed Hard Palate Closure. *Scandinavian journal of plastic and reconstructive surgery and hand surgery*, 32(1), 63-80.

Luke, L. T. (2018). Cleft palate repair by double opposing Z-plasty. *Plastic and Reconstructive Surgery*, *78*(6), 724-738.

Marazita, M. L. (2012). The Evolution of Human Genetic Studies of Cleft Lip and Cleft Palate. *Annual Review of Genomics and Human Genetics*, 13, 263–283. http://doi.org/10.1146/annurev-genom-090711-163729

Marshall, C., & Rossman, G. (2010). *Designing Qualitative Research.* New Jersey: Sage Publications.

Medical Journal of the Islamic Republic of IRAN; *Speech intelligibility after repair cleft lip and palate*; 2017.

Medina, A. M., & Mead, J. S. (2021). An Exploration of Mindfulness in Speech-Language Pathology. *Communication Disorders Quarterly*. https://doi.org/10.1177/1525740120942141

Michael, W. E. M. (2017). The technique of operation for cleft palate. *British Journal of Surgery*, *25*(97), 117-130.

Mossey P, Castillia E. Geneva CH (2003). World Health Organization; *Global Registry and Database on Craniofacial Anomalies.*

Mugenda, A., & M. (2009). Research Methods: Quantitative and Qualitative Approaches. In *Acts Press Publishers.*

Murthy, J. (2009). Management of cleft lip and palate in adults. In *Indian Journal of Plastic Surgery*. https://doi.org/10.4103/0970-0358.57202

Ndung'u, R., & Kinyua, M. (2009). Cultural Perspectives in Language and Speech Disorders. *Disability Studies Quarterly*. https://doi.org/10.18061/dsq.v29i4.986

P. Agbenorku, "Orofacial Clefts: A Worldwide Review of the Problem," ISRN Plastic Surgery, vol. 2013, Article ID 348465, 7 pages, 2013. https://doi.org/10.5402/2013/348465.

Palomares-Aguilera, M., Inostroza-Allende, F., & Solar, L. R. (2021). Speech pathology telepractice intervention during the COVID-19 pandemic for Spanish-speaking children with cleft palate: A systematic review. In *International Journal of Pediatric Otorhinolaryngology*. https://doi.org/10.1016/j.ijporl.2021.110700

Panamonta, V., Pradubwong, S., Panamonta, M., & Chowchuen, B. (2015). Global Birth Prevalence of Orofacial Clefts: A Systematic Review. In *Journal of the Medical Association of Thailand = Chotmaihet thangphaet*.

Pedersen, H. M., Goodie, P. A., Braden, M. N., & Thibeault, S. L. (2021). Comparing Quality of Life and Perceptual Speech Ratings in Children With Cleft Palate. *Cleft Palate-Craniofacial Journal*. https://doi.org/10.1177/1055665620949435

Peterson-Falzone, S. J, Hardin-Jones, M. A, Karnell, M. P. (2010). *Cleft palate speech.* 4th ed. St. Louis, MO: Mosby-Elsevier; 2010.

Rhodes, J. L., & Staffenberg, D. A. (2009). Complications in Cleft Lip and Palate Surgery. In *Complications in Head and Neck Surgery* (pp. 279-287). Mosby.

Rieger, J., Dickson, N., Lemire, R., Bloom, K., Wolfaardt, J., Wolfaardt, U., & Seikaly, H. (2006). Social perception of speech in individuals with oropharyngeal reconstruction. *Journal of Psychosocial Oncology*. https://doi.org/10.1300/J077v24n04_03

Ryan, M. K., & Branscombe, N. R. (2013). Researh Methodology. *The SAGE Handbook of Gender and Psychology*.

Sarah, & Annette L, (2011). *Cleft palate speech*: Assessment and Interventions.

Schreiber, J. (2018). Orofacial Clefts May Be a Window Into Identifying Common Psychopathology Development. In *Journal of the American Academy of Child and Adolescent Psychiatry*. https://doi.org/10.1016/j.jaac.2018.08.009

Sell, D. (2005). Issues in perceptual speech analysis in cleft palate and related disorders: A review. International Journal of Language & Communication Disorders, 40(2), 103-121.

Shprintzen R. J & Bardach,. J. (1995), *Cleft Palate Speech Management:* A Multidisciplinary Approach

Sitzman, T. J., Allori, A. C., & Thorburn, G. (2014). Measuring outcomes in cleft lip and palate treatment. *Clinics in plastic surgery*, *41*(2), 311-319.

Sousa, A. De, Devare, S., & Ghanshani, J. (2009). Psychological issues in cleft lip and cleft palate. In *Journal of Indian Association of Pediatric Surgeons*. https://doi.org/10.4103/0971-9261.55152

Suleiman, A. M., Hamzah, S. T., Abusalab, M. A., & Samaan, K. T. (2005). Prevalence of cleft lip and palate in a hospital-based population in the Sudan. *International Journal of Paediatric Dentistry*. https://doi.org/10.1111/j.1365-263X.2005.00626.x

Swann, W. B. (2012). Self-verification theory. In *Handbook of Theories of Social Psychology*. https://doi.org/10.4135/9781446249222.n27

Taherdoost, H. (2018). Sampling Methods in Research Methodology; How to Choose a Sampling Technique for Research. *SSRN Electronic Journal*. https://doi.org/10.2139/ssrn.3205035

Thyer, B. A., Franklin, C. S., Cody, P. A., & Ballan, M. (2019). Reliability and Validity in Qualitative Research. In *The Handbook of Social Work Research Methods*. https://doi.org/10.4135/9781544364902.n19

W.A, (2014), Cleft Palate and Craniofacial Anomalies: *Effects on Speech and Resonance*.3rd edition.

Wang, M., Yuan, Y., Wang, Z., Liu, D., Wang, Z., Sun, F., Wang, P., Zhu, H., Li, J., Wu, T., & Beaty, T. H. (2017). Prevalence of Orofacial Clefts among Live Births in China: A Systematic Review and Meta-Analysis. In *Birth Defects Research*. https://doi.org/10.1002/bdr2.1043

Wanjeri, J. K. (2018). How partnerships are helping cleft lip and palate surgeries in Kenya: Conversation Academic Rigour, *Journalistic flair.*

Watson A. Sell D., Grunnwell P., (2001). *Management of Cleft lip and palate:* University of Michigan. WHO (World Health Organization). Measuring quality of life. *The World Health Organization quality of life instruments.* WHO/MSA/MNH/PSF; 2015.p. 1---15.

Wong, L. S., Lim, E., Lu, T. C., & Chen, P. K. T. (2019). Management of velopharyngeal insufficiency by modified Furlow palatoplasty with pharyngeal flap: a retrospective outcome review. *International Journal of Oral and Maxillofacial Surgery*. https://doi.org/10.1016/j.ijom.2019.01.010

World Health Organization Quality of Life (WHOQOL) Group, 1994 World Health Organization Quality of Life (WHOQOL) Group Development of the WHOQOL: rationale and current status. *Int. J. Ment. Health, 23* (3) (1994), pp. 24-56

Xie, D. X., Wang, R. Y., & Chinnadurai, S. (2017). Readability of online patient education materials for velopharyngeal insufficiency. *International Journal of Pediatric Otorhinolaryngology*. https://doi.org/10.1016/j.ijporl.2017.09.016

Zainal, Z. (2003). Case study as a research method. *Jurnal kemanusiaan*, *5*(1).

Zajac, J. D., & Vallino, D. L. (2017). *Evaluation and Management of cleft lip and palate:*

Zhang, Z., Stein, M., Mercer, N., & Malic, C. (2017). Post-operative outcomes after cleft palate repair in syndromic and non-syndromic children: A systematic review protocol. *Systematic Reviews*. https://doi.org/10.1186/s13643-017-0438-2 Centers for Disease Control and Prevention (CDC) 2006. Improved national prevalence estimates for 18 selected major birth defects, United States, 1999–2001. *MMWR Morb Mortal Wkly Rep.;* 54:1301–1305.

APPENDICES

Appendix I: Informed Consent

My Name is **Irene Gatwiri Bundi**. I am Master's Student from Kenyatta University. I am conducting a study on "**Effects of Velopharyngeal Insufficiency on quality of life of adults with repaired cleft Palate in Kenyatta National Hospital, Nairobi Kenya**''. The information will be used by the Ministry of Health to adopt better treatment strategies for persons who have undergone cleft palate repair in the Hospital and other regions in Kenya.

Procedures to be followed

Participation in this study will require I ask you questions and will record the information in a questionnaire.

You have the right to refuse to participate in this study. You will get the same care and medical treatment whether you agree to join the study or not.

Participation in this study is voluntary and questions related to the study are encouraged.

Discomforts and risks

Some of the questions may make you uncomfortable. If this happens to be the case, you may choose not to answer. Filling of the questionnaire may take 30 minutes of your time.

Benefits

Your participation in this study will lead to creation of better protocols in management of persons with cleft palate thus improving their quality of life.

Confidentiality

Your identity will be kept confidential and the information that you provide will be coded.

Upon completion of this study, information given will be kept under lock and your name will not be used under any publication.

Contact information

If you have any questions you may contact Dr. Karia - Supervisor 1. On 0721-210692 and/or Dr. Aboum Supervisor 2. On 0727 254524. OR Kenyatta University Ethical Review Committee Secretariat on chairman.kurc@ku.ac.ke

Participant's statement

The above information regarding my participation in the study is clear to me. I have been given a chance to ask questions and have been answered to my satisfaction. My participation in this study is entirely voluntary.

Code of participant……

…… ……

Signature or thumb print Date

Investigator`s Statement

I, the undersigned, I have explained to the volunteer in a language she/he understands, the procedures to be followed in the study and the risks and benefits involved.

Name of interviewer…….

……. …….

Interviewer signature Date

Appendix II: Questionnaire for Patients

This questionnaire is aimed at collecting data on the influence of velopharyngeal insufficiency on of quality of life of adults with repaired/unrepaired cleft palate in Kenyatta National Hospital. The data will be used for academic purpose only and will be treated with strict confidence. You are kindly requested to participate in the study by providing answers to the items in the sections as indicated.

In the past four weeks, how much of a problem have you have with (circle one for each question):

INSTRUCTIONS:

All the information provided here will be considered private and confidential, will be used for research purpose **ONLY**.

Please indicate the most appropriate choice of answer by putting a tick in the box provided

SECTION A: Personal Information

1. Age: _____
2. Gender: Male ☐ Female ☐
3. Education level: None ☐ Primary ☐ Secondary ☐ Tertiary ☐
4. Marital Status: Married ☐ Single ☐ Divorced/Separated ☐ Widow(er) ☐
5. VPI severity: None ☐ Minimal ☐ Mild ☐ Moderate ☐ Severe ☐
6. Mis-articulation: None ☐ Minimal ☐ Mild ☐ Moderate ☐ Severe ☐

SECTION B: Functional Ability

Please indicate on Likert Scale the extent to which you agree with the following statement.

Talking (problems with…)		**Never**	**Almost Never**	**Some times**	**Often**	**Almost Always**
1.	Air comes out of nose when I talk					
2.	I run out of breath when I talk					
3.	It is hard talking in long sentences					
4.	My speech is too weak					
5.	I have trouble being understood when I'm in a hurry					
6.	My speech gets worse toward the end of the day					
7.	My speech sounds different than other people					
Swallowing (problems with…)						
8.	Liquids comes out of my nose while drinking					
9.	Food comes out of my nose while eating					
10	Others make fun of me when food or liquids come of my nose					

Times when I have trouble (problems with…)						
11.	My speech is hard for strangers to understand					
12.	My speech is hard for friends to understand					
13.	My speech is hard for family to understand					
14.	I have trouble being understood when others can't see my face, for example, in a car					
15.	I have trouble being understood on the phone					
How I feel (problems with…)						
16.	I am teased because of the way I talk					
17.	I get sad because of how I talk					
18.	I get frustrated or give up when I am not understood					
19.	I am shy because of how I talk					
How others feel about me (problems with…)						
20.	I am treated like I am not a smart person because of how I talk					
21.	Others ignore me because of how I talk					

22.	Others do not like to talk on the phone with me because of how I talk					
23.	My family or friends tend to talk for me					

Section C: Social Interaction

Key: Strongly Disagree (SD), Disagree (D), Agree (A), Strongly Agree (SA)

No	Items	SD	D	A	SA
1.	I have challenges in making friends.				
2.	I do not find social interaction enjoyable.				
3.	I have difficulties in initiating positive interaction with their peers.				
4.	I exclude myself from social gatherings.				
5.	I like to have friends but am unable to make some friends.				

Appendix III: Interview Based for Maxillofacial Surgeons

This interview is aimed at gathering information about the **Effects of Velopharyngeal insufficiency on quality of life of adults with repaired cleft palate in Kenyatta National Hospital,** The information will be held in total confidence and will be used for the purposes of this study.

1. What services are available for patients in the improvement of quality life after cleft palate repair?

2. Are there treatment options that you would recommend but not available within this setting, if yes, which methods and why?

3. What are the challenges you face in habilitation of speech production after cleft palate repair?

4. What methods do you use towards improvement of speech production on patients after cleft palate repair?

5. What are the current methods towards improvement of quality of life of patients after cleft palate repair practiced today?

Appendix IV: Interview Based for Speech and Language Therapist

This interview was aimed at gathering information about **The Role of speech therapy on communication of patients with repaired cleft palate**. The information will be held with total confidentiality and will be used for the purposes of study.

1. What approaches do you use in the assessment of VPI?
2. What are the available procedures utilized in the treatment of VPI?
3. What speech therapy procedure is commonly used to treat VPI?
4. What challenges do you face in the rehabilitation of speech, for patients experiencing VPI?
5. What other methods would you recommend towards the management of VPI?

APPENDIX V: PERMIT FROM NACOSTI

REPUBLIC OF KENYA

NATIONAL COMMISSION FOR
SCIENCE,TECHNOLOGY & INNOVATION

Ref No: **690518**

Date of Issue: **14/August/2019**

RESEARCH LICENSE

This is to Certify that Miss.. IRENE BUNDI of Kenyatta University, has been licensed to conduct research in on the topic: EFFECTS OF VELOPHARYNGEAL INSUFFICIENCY ON QUALITY OF LIFE OF ADULTS WITH REPAIRED CLEFT PALATE IN KENYATTA NATIONAL HOSPITAL, NAIROBI, KENYA EFFECTS OF VELOPHARYNGEAL INSUFFICIENCY ON QUALITY OF LIFE OF ADULTS WITH REPAIRED CLEFT PALATE IN KENYATTA NATIONAL HOSPITAL, NAIROBI, KENYA EFFECTS OF VELOPHARYNGEAL INSUFFICIENCY ON QUALITY OF LIFE OF ADULTS WITH REPAIRED CLEFT PALATE IN KENYATTA NATIONAL HOSPITAL, NAIROBI, KENYA for the period ending : 14/August/2020.

License No: **NACOSTI/P/19/455**

690518

Applicant Identification Number

Director General
NATIONAL COMMISSION FOR
SCIENCE,TECHNOLOGY &
INNOVATION

Verification QR Code

NOTE: This is a computer generated License. To verify the authenticity of this document, Scan the QR Code using QR scanner application.

Appendix VI: Approval Letters

KENYATTA UNIVERSITY
ETHICS REVIEW COMMITTEE

Fax: 8711242/8711575
Email: kuerc.chairman@ku.ac.ke

P. O. Box 43844,
Nairobi, 00100
Tel: 8710901/12

Website: www.ku.ac.ke

Our Ref: **KU/ERC/ APPROVAL /VOL.1/279** Date: 15th July, 2019

Irene Gatwiri Bundi
P.O Box 43844-00100
NAIROBI

Dear Ms. Bundi,

APPLICATION NUMBER: PKU/1045/I1095 EFFECTS OF VELOPHARYNGEAL INSUFFICIENCY ON QUALITY OF LIFE OF ADULTS WITH REPAIRED CLEFT PALATE IN KENYATTA NATIONAL HOSPITAL, NAIROBI, KENYA

1. **IDENTIFICATION OF PROTOCOL**

The application before the committee is with a research topic "**Effects Of Velopharyngeal Insufficiency On Quality Of Life Of Adults With Repaired Cleft Palate In Kenyatta National Hospital, Nairobi, Kenya** " received on 06/6/2019 and discussed on 9th July, 2019

2. **APPLICANT**

Irene Gatwiri Bundi

3. **SITE**

Kenyatta National Hospital, Nairobi, Kenya

4. **DECISION**

The committee has considered the research protocol in accordance with the Kenyatta University Research Policy (section 7.2.1.3) and the Kenyatta University Ethics Review Committee Guidelines and **APPROVED that the research may proceed for a period of ONE year from 9th June, 2019.**

5. ADVICE/CONDITIONS

i. Progress reports are submitted to the KU-ERC every six months and a full report is submitted at the end of the study.
ii. Serious and unexpected adverse events related to the conduct of the study are reported to this committee immediately they occur.
iii. Notify the Kenyatta University Ethics Committee of any amendments to the protocol.
iv. Submit an electronic copy of the protocol to KUERC.

When replying, kindly quote the application number above.
If you accept the decision reached and advice and conditions given please sign in the space provided below and return to KU-ERC a copy of the letter.

PROF. JUDITH KIMIYWE
CHAIRMAN ETHICS REVIEW COMMITTEE

I ...IRENE GATWIRI BUNDI.....accept the advice given and will fulfill the conditions therein.

Signature..... Dated this day of.....22/7/2019..... 2019.

cc.
DVC-Research Innovation and Outreach

KENYATTA UNIVERSITY
GRADUATE SCHOOL

E-mail: dean-graduate@ku.ac.ke
Website: www.ku.ac.ke

P.O. Box 43844, 00100
NAIROBI, KENYA
Tel. 020-8704150

Our Ref: E55/38201/2016

DATE: 27th May, 2019

Director General,
National Commission for Science, Technology
and Innovation
P.O. Box 30623-00100
NAIROBI

Dear Sir/Madam,

RE: RESEARCH AUTHORIZATION FOR MS. IRENE GATWIRI BUNDI – REG. NO. E55/38201/2016

I write to introduce Ms. Irene Gatwiri Bundi who is a Postgraduate Student of this University. She is registered for M.Ed. degree programme in the **Department of Early Childhood & Special Needs Education.**

Ms. Bundi intends to conduct research for a M.Ed. thesis Proposal entitled, **"Effects of Velopharyngeal Insufficiency on Quality of Life of Adults with Repaired Cleft Palate in Kenyatta National Hospital, Nairobi, Kenya."**

Any assistance given will be highly appreciated.

Yours faithfully,

KENYATTA UNIVERSITY OFFICE OF DEAN 29 MAY 2019 GRADUATE SCHOOL P.O. Box 43844-00100

PROF. ELISHIBA KIMANI
DEAN, GRADUATE SCHOOL

HI/cww

KENYATTA UNIVERSITY
GRADUATE SCHOOL

E-mail: dean-graduate@ku.ac.ke
Website: www.ku.ac.ke
P.O. Box 43844, 00100
NAIROBI, KENYA
Tel. 020-8704150

Internal Memo

FROM: Dean, Graduate School

DATE: 27th May, 2019

TO: **Ms. Irene Gatwiri Bundi**
C/o Early Childhood & Special Needs Education Dept.

REF: E55/38201/2016

SUBJECT: APPROVAL OF RESEARCH PROPOSAL

This is to inform you that Graduate School Board, at its meeting on **22nd May, 2019,** approved your Research Proposal for the M.Ed. Degree entitled, **"Effects of Velopharyngeal Insufficiency on Quality of Life of Adults with Repaired Cleft Palate in Kenyatta National Hospital, Nairobi, Kenya."**

You may now proceed with your Data collection, subject to clearance with the Director General, National Commission for Science, Technology & Innovation and Director, Ethical Committee, Kenyatta University.

As you embark on your data collection, please note that you will be required to submit to Graduate School completed Supervision Tracking Forms per semester. The form has been developed to replace the Progress Report Forms. The Supervision Tracking Forms are available at the University's Website under Graduate School webpage downloads.

Thank you.

KENYATTA UNIVERSITY OFFICE OF DEAN 29 MAY 2019 GRADUATE SCHOOL P.O. BOX 43844-00100 NAIROBI

HARRIET ISABOKE
FOR: DEAN, GRADUATE SCHOOL

CC. Chairman, Early Childhood & Special Needs Education Department
Supervisors:

1. Dr. Mathew Karia
   C/o Dept. of Early Childhood & Special Needs Education
   Kenyatta University

2. Dr. Tom Abuom
   C/o Dept. of Early Childhood & Special Needs Education
   Kenyatta University

HI/ciww

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KENYATTA NATIONAL HOSPITAL APPROVED 25 NOV 2019 KNH/UoN-ERC P. O. BOX 20723 - 00202 NAIROBI

Ref: KNH-ERC/A/448

25th November, 2019

Irene Gatwiri Bundi
Reg. No.E55/38201/2016
Dept. of Early Childhood and Special Needs Education
School of Education
Kenyatta University

Dear Irene

RESEARCH PROPOSAL: EFFECTS OF VELOPHARYNGEAL INSUFFICIENCY ON QUALITY OF LIFE OF ADULTS WITH REPAIRED CLEFT PALATE IN KENYATTA NATIONAL HOSPITAL, NAIROBI, KENYA (P534/07/2019)

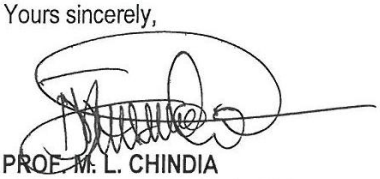
This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above research proposal. The approval period is 25th November 2019 – 24th November 2020.

This approval is subject to compliance with the following requirements:

a. Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
b. All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
c. Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
d. Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
e. Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
f. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
g. Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

For more details consult the KNH- UoN ERC website**http://www.erc.uonbi.ac.ke**

Yours sincerely,



PROF. M. L. CHINDIA
SECRETARY, KNH-UoN ERC

c.c. The Principal, College of Health Sciences, UoN
The Director, CS, KNH
The Chairperson, KNH- UoN ERC
The Assistant Director, Health Information, KNH
Supervisors: Dr.Mathew Karia, Dept. of Early Childhood and Special Education, Kenyatta University
Dr.Tom Abuom, Dept. of Early Childhood and Special Education, Kenyatta University