

**CAREGIVERS' INVOLVEMENT IN INTERVENTION PROGRAMS
FOR CHILDREN WITH SPEECH AND LANGUAGE DISORDERS IN
TENWEK HOSPITAL, BOMET COUNTY, KENYA**

BY

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E55/27869/2014

**A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE AWARD OF THE DEGREE OF MASTER
OF EDUCATION (SPEECH AND LANGUAGE PATHOLOGY) IN THE
SCHOOL OF EDUCATION AT KENYATTA UNIVERSITY**

OCTOBER, 2018

DECLARATION

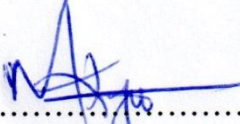
I declare that this is my original work and it has not been presented for certification in any other university or institution. This research thesis has been complemented by referenced sources duly acknowledged.

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ACKNOWLEDGEMENTS

I wish to express my sincere appreciation to all individuals whose contributions made the completion of this thesis possible. I am extremely humbly indebted to my supervisors Dr. Mathew Karia and Dr. Tom Abuom for their scholarly guidance, assistance, tireless devotion and encouragement throughout the course of my studies.

My very special thanks go to all my lecturers in the Department of Special Needs Education at Kenyatta University for their encouragement particularly to the Chairperson, Dr. Nelly Otube on her most constant reminder and encouragement. Thanks to Dr. Nyamasyo and Dr. Wamocho whose advice and encouragement for the initiation of the study stand. Special thanks to the readers of my proposal whose guidance has remained the foundation of this thesis, Prof. Karugu and Dr. Bunyasi; God bless them. Appreciation goes to all my classmates in the Department of Special Needs Education, Charles, Gregory and Alusiah. I wish to express my sincere gratitude to my loving family for the great support both psychological and resources.

My special gratitude goes to the Medical Superintendent and chair of Tenwek Ethical Research Committee, Dr. Burgert for approving my proposal, Faith and Woody Rule- speech-language pathologist, Solomon Rop- Physiotherapist, Tenwek Mission Hospital and all caregivers of children with communication disorders for a remarkable support. Special thanks to my God for enabling me to work and to have given me the strength to produce this thesis.

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ABBREVIATIONS AND ACRONYMS

CDI	Child Development Institute
NPT	Normalization Process Theory
PT	Occupation Therapist
SLP	Speech and Language and Pathology
WHO	World Health Organisation

ABSTRACT

The purpose of this study was to establish caregivers' involvement intervention programs for children with speech and language disorders in Tenwek Hospital, Bomet County. The objectives of the study sought to investigate caregivers' awareness of speech and language disorders intervention for children with speech and language disorders; to establish the extent of caregivers' involvement in intervention program for children with speech and language disorders; to find out the barriers to caregivers' involvement in intervention program for children with speech and language disorders and also to establish caregivers' needs for involvement in intervention program for children with speech and language disorders. The study was guided by Normalization Process Theory by May, (2006). The study adopted a case study research design. The study used accessible population of 62 respondents comprising of caregivers and two Tenwek outpatient clinic therapists in Bomet County. The study employed purposive sampling technique and utilised all the accessible population. The instruments' validity was verified and reliability tested through piloting. The pilot study used one therapist purposively selected and six randomly selected caregivers. Sixty (60) caregivers and two therapists formed the study population. Data was collected by administering questionnaires to the caregivers and interview guides to therapists. Quantitative data was analysed using descriptive statistics in form of frequency counts, percentages and tables with the aid of SPSS computer program while qualitative data was analysed thematically. The study found that despite caregivers' awareness of their children's disorder, majority were not conversant with the cause and treatment of the disorder. Caregivers were involved in the intervention mainly by attending therapy appointments, communicating with staff in decision making and parent-child therapy. Caregivers were mostly barred from effective involvement by financial constraints and other children in the household. Though they were satisfied with the rehabilitation process, they mostly needed financial empowerment and capacity building. In conclusion, caregiver empowerment and participation need to become integral components of early intervention services for young children with speech and language disorders. Caregivers' individual needs should be considered and adequate support given by clinician. The study recommends need for more public sensitization on the cause, signs, prevention mechanisms and best therapy treatment programs available for children with speech and language disorders.

CHAPTER ONE:

INTRODUCTION AND BACKGROUND OF THE STUDY

1.0. Introduction

This Chapter describes the background of the study, problem statement, purpose of the study, research objectives, research question, study significance, study assumptions, limitation and delimitation/scope of the study as well as operational definition of key terms.

1.1. Background to the Study

Since young children benefit from early identification of communication disorders, parents and guardians herein referred to as caregivers become the integral part of the intervention services provided (Downs, & Yoshinaga-Itano, 1999). Informal, but continuous and consistent efforts to involve caregivers in intervention programs results in an improved communication skills of the child. Involvement of caregivers (parents and guardians) includes; decision making, attending appointments, trainings/workshops, counselling, clinical communication and participating in therapeutic activities (Kolt & McEvoy, 2007).

Caregivers who are empowered tend to contribute effectively towards the child's literacy and coaching on the communication disorders. This improves the child's communication skills and literacy. Caregivers' involvement

enhances effective early intervention in terms of taking part in therapeutic activities, communication notes, adherence to appointments and training the child (Roberts & Kaiser, 2011). The success of early intervention result to child's improved communication skills and literacy. Caregivers' capacity building and active participation should be integrated as major components of early intervention program for children with speech and language disorders.

Early intervention in speech and language disorder is meant to prevent communication disability and enhance functional ability in activities of daily living as substantial gains may be achieved when treatment is provided at a very early age (Allen & Duncan-Smith, 2008). It involves the use of speech and language as a tool of communication, thereby improving quality of life for both the child and the family (Leitao & Fletcher, 2004). Research has found that early speech and language disorders impacts negatively on children's development and literacy (Conti-Ramsden, Botting, Simkin & Knox, 2001).

Speech and language disorders can impact negatively on the social life of a child in the short and long term. Long-term effects of communication disorders become profound when disorders are not resolved at early age (Snowling, Adams, Bishop, & Stothard, 2001). Speech and language disorders are major problems experienced by children at risk of communication disorders and these results to persistent educational and social difficulties (Locke, Ginsborg & Peers, 2002). Early intervention therefore, helps in off-setting problems associated to speech and language disorders.

According to World Health Organisation and World Bank, (2011), the world population estimates between 1.1-1.9 million of individuals that may have severe communication disorders. Although some of these disorders may be supported sufficiently, there are some that are not served due to the limited rehabilitation healthcare providers in third world countries (WHO & World Bank, 2011). Wide variation in rehabilitation support for people with communication disorders has been noted in 29 African countries due to uncoordinated service delivery, limited service access at local level, and a persistent need for development support (WHO & World Bank, 2011).

Lack of Speech and Language Pathologists (SLP) in most African countries is recorded, with one per two to four million people particularly in rural areas (Wylie, McAllister, Marshall, Wickenden, & Davidson, 2012). Speech and Language Pathology service provision in East African countries with an estimated population of 141.8 million (WHO & World Bank, 2011), is majorly confined to urban areas and usually practised in private health care. Those who reside in rural areas find it difficult accessing service. Physical barriers, such as, poor transport network, informational for instance, ignorance of available support, or insufficient funds for travel, (Makinen, Waters, Rauch, Almagambetova, Bitran, Gilson & Ram, 2000); or accessibility to private care, hinders access to treatment. Considering these difficulties of limited service, responsibility for the child's early speech and language disorders intervention and welfare usually falls to the parents (primary caregivers).

The involvement of caregivers and families of children with communication disorders is vital for any effective early intervention services. In most cases, caregivers and the familiar context of children with communication disorders experience social isolation and emotional disturbance, along with the really practical challenges of handling their children. These challenges interfere with familiar context, thus compounding the children's disorders (CDI, 2010). Caregivers and family members need to take a crucial role in intervention programmes for children with communication disorders.

Caregivers should be included as the main participants in the intervention services of the children since they are more informed of the child's capabilities and limitations, though informally. They have more time with the child and frequent interactions in the physical environment. They are also presumed to be willing to use their resources for the well-being of the child as parent/guardian (Girolametto, Wiigs, Smyth, Weitzman & Pearce, 2001; Girolametto & Weitzman, 2006). The current study sought to find out caregivers awareness about speech and language disorders and treatment procedures as they play an integral role in intervention in Tenwek Hospital.

Research has shown that caregivers' engagement is crucial for child's holistic development and literacy; however there are barriers to effective engagement (Desforges & Abouchaar, 2003). Although little research has been done on Rural Kenyans' Attitude towards communication disorders and therapy in Teso community Western Kenya (Gill, 2009) and Kilifi in Coastal Kenya (Bunning, Gona, Newton, and Hartley, 2014), studies in Kenya have not investigated

caregivers' involvement in early intervention programs for children with speech and language disorders and the barriers to effective engagement(Glogowska & Campbell, 2000).

The child acquires early life experience through interpersonal interactions. The child's speech and language development and potential for intellectual, emotional, and social skills development is dependent on the quality and quantity of interaction with the caregivers, (Shonkoff & Hauser-Cram, 1987). Caregivers' involvement is regarded as a crucial component in intervention process since it builds a sense of satisfaction on early intervention efficacy. In Kenya, little emphasis has been given to caregivers' role in early intervention for speech and language disorders due to lack of research on caregivers involvement (Bunning et al., 2014). Considering the importance of communication in a child's life, there is a need to explore family practices that have an impact on a child's speech and language development.

Children with speech and language disorders in rural areas, Bomet County have not been well attended. However, with the opening of Tenwek Special Needs Outpatient Clinic at the hospital and through a mobile clinic at Bomet primary school has enhanced speech and language pathology services. Approximately 60 children from Bomet County have been served by the clinic as reported in Tenwek Mission Hospital records, 2015. Diagnoses have included autism, pervasive developmental disorder, cerebral palsy, spina bifida, and other developmental disabilities associated with speech and language disorders. Therefore, the current research sought to establish the extent of

caregivers' involvement in intervention program for children with speech and language disorders and the barriers to effective engagement in Tenwek Mission Hospital, Bomet County Kenya.

1.2. Statement of the Problem

Children with speech and language disorders together with their families experience emotional turmoil and social isolation. They also experience practical challenges of managing the effects of speech and language disorders. These challenges affect both the social and economic dynamics of the affected families thereby compounding the children's communication limitations. Speech and language disorders affect the child's social skills, communication, behaviour development as well as literacy. Caregivers (parents/guardians) are vital participants in the rehabilitation process of children since they are more informed of their children's abilities and limitations since they are presumed to have more frequent interactions with them. The speech and language of a child develops due to early life experiences in an interpersonal relationship. Language development depends on the quality and quantity of interaction with parents/guardians and other members of the family who happens to be the most important people in their lives.

In Kenya, the awareness about speech and language disorders, level of caregivers' involvement in rehabilitation services, barriers to involvement as well as needs and wants of caregivers is not clear. Little research has been done on caregivers' attitude on communication disorders and therapy in Coastal and Western region. Further research need to focus on caregivers' awareness of speech and language disorders and treatment. Caregivers' involvement in early intervention, barriers to effective involvement as well as caregivers' needs for involvement in intervention program. Considering the importance of speech

and language development in the child's life, there is need to investigate caregivers' involvement on intervention programs for children with speech and language disorders.

Children with speech and language disorders in rural areas of Bomet County have not been well attended to. Following the need, speech and language pathology rehabilitation has been initiated through an outpatient clinic in Tenwek Mission Hospital and a mobile clinic at Bomet Primary School. The main objective for this initiative is to avail therapy services and engage the caregivers to alleviate speech and language disorders. However, it is not clear the extent to which the caregivers are involved in early intervention therapy for their children with speech and language disorders. Therefore; this study sought to establish caregivers' involvement in intervention programs for children with speech and language disorders in Tenwek Hospital, Bomet County.

1.2.1. Purpose of the Study

The purpose of this study was to establish the caregivers' involvement in intervention programs of children with speech and language disorders in Tenwek Hospital, Bomet County.

1.2.2. Research Objectives

The objectives of the study were to:

- i. Investigate the caregivers' awareness of speech and language disorders intervention process in Tenwek Hospital, Bomet County.
- ii. Establish the extent of caregivers' involvement in intervention program for children with speech and language disorders in Tenwek Hospital, Bomet County.
- iii. Find out the barriers to caregivers' involvement in intervention program for children with speech and language disorders in Tenwek Hospital, Bomet County.
- iv. Investigate caregivers' needs for involvement in intervention program for children with speech and language disorders in Tenwek Hospital.

1.2.3. Research Questions

- i. What is caregivers' awareness of speech and language disorders intervention process in Tenwek Hospital, Bomet County?

- ii. What is the extent of caregivers' involvement in intervention program for children with speech and language disorders in Tenwek Hospital, Bomet County?
- iii. What are the barriers to caregivers' involvement in intervention program for children with speech and language disorders in Tenwek Hospital, Bomet County?
- iv. What are caregivers' needs for involvement in intervention program for children with speech and language disorders in Tenwek Hospital?

1.3. Significance of the Study

The research findings of this study may give an insight on the best approach to caregivers' involvement and the extent of involvement in planning and implementation of early intervention programs on speech and language therapy. It also provides more information on the importance of caregivers' involvement and their relevance in early intervention services for the children with speech and language disorders in Bomet County and Kenya at large. It further assists caregivers on building knowledge about speech and language pathology and creates a positive attitude towards early interventions. Finally, it adds to knowledge and provides literature to the government, non-governmental organizations, universities and other scholars on caregivers' vital role in paediatric speech and language intervention.

1.4.0. Limitations and Delimitations

1.4.1. Limitations

The study targeted caregivers of children with speech and language disorders whose children are rehabilitated in Tenwek Mission Hospital only in Bomet County. Therefore, application of the study findings to other caregivers in other counties should be done with caution. Due to inaccessibility to speech therapist in Bomet County, the pilot study was carried out in a neighbouring County of Vihiga with a similar rehabilitation services.

1.4.2. Delimitation

The study targeted all caregivers of the children with speech and language disorders who bring their children or the children they care for rehabilitation to Tenwek Mission Hospital in Bomet County. This was because Tenwek is the largest hospital in the county which provides the needed services for the children with speech and language disorders. The respondents to the questionnaires of this study were parents or guardians of children with speech and language disorders, herein referred to as the caregivers and two therapist i.e. speech and language therapist and physiotherapist.

1.5. Assumptions

The study was undertaken with the following assumptions:

1. That the respondents to the study gave honest information.

2. That the respondents had clear and diverse views/information regarding the disorders under study.

1.6. Theoretical Framework

This study was guided by Normalization Process Theory (May, 2006). Normalization Process Theory (NPT) has been extensively used to explain the link that exists between different entities in the implementation innovations in healthcare sector. It was developed from Normalization Process Model (NPM), to help healthcare providers and researchers to comprehend and evaluate entities that inhibit and promote routine incorporation of individual actors in healthcare interventions (May, 2006). May's interest was to understand the role of individuals and collective actors so as to normalize the innovation as part of routine practice in the context of healthcare delivery. The collective action, as explained by May in the theory, advocates for involvement of different actors in the intervention (caregivers, patient, provider, and other healthcare workers). The current study used the collective action to investigate the extent of caregivers' involvement in intervention programs which may influence early intervention efficacy.

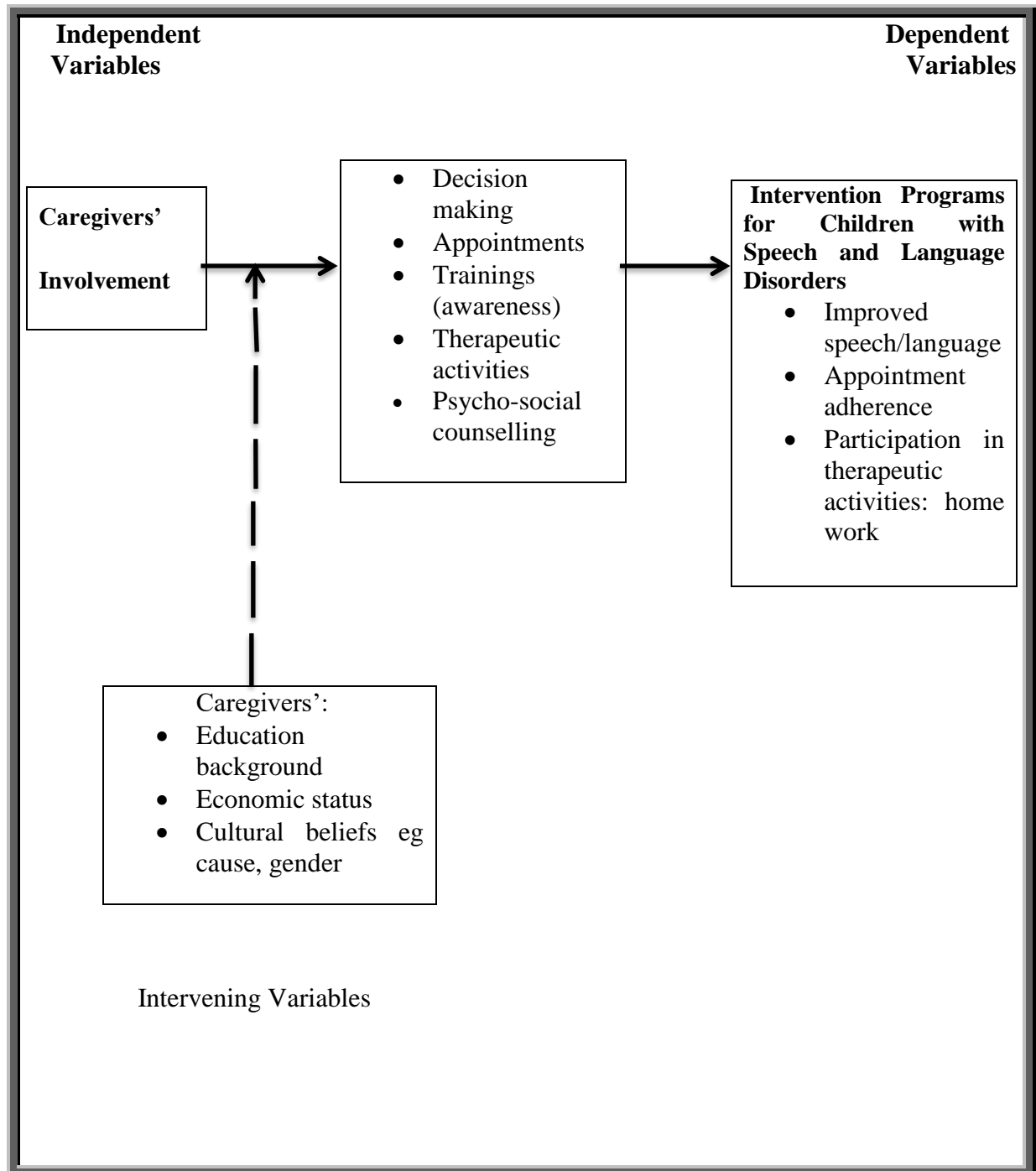
NPT does not only concentrate on the transfer and creation of knowledge within and across professional groups, but it also seeks to understand the role various actor indulge in to implement new knowledge in practice. Knowledge dissemination among actors (clinician and caregivers) improves caregivers understanding of the disorder and communication. The current study benefited

from the theory by exploring the extent of caregivers' involvement which had an impact on the effectiveness of early intervention services. It concentrates on legitimate intervention and the role of caregivers in intervention process. Through its tenets of; collective action and the role of actors in normalisation process, it explains the significance of involving caregivers in early intervention process for it to be effective (improved speech and language).

It is critical to consider the complexity in which interventions for speech and language are delivered. This determines how early intervention strategies ought to be designed and integrated to meet particular needs and expectations of the clients and their families. According to May and Finch, (2009), early interventions in terms of speech and language therapy are likely to be integrated if they attain a substantial level of flexibility in its internal elements of the intervention. The main tenets that have to be incorporated include: professional-patient relationships; new care delivering modalities; social construction and evidence production; and social organisation of clinical work. It includes tenets like; establishment of the meaning of the intervention, agreement on the manner of intervention delivery, and evaluation on the effectiveness of the intervention between the participants.

NPT's provisions of collective action, actors' role in intervention and system normalisation formed the basis of understanding the conceptual framework of this study. The current study integrated NPT's tenets to investigate the benefits of caregivers (actors) role, their level of involvement for better early

intervention process, barriers to involvement and their wants and needs for effective involvement.



Source: Researcher's 2016

Figure 1.1 Conceptual Framework

The conceptual framework puts the study within a concept as per the variables for easy conceptualization of the entire study. It is based on the fact that the involvement of caregivers of children with speech and language disorders in early intervention programs will improve service delivery both at the clinic level and home services. The model focuses on the leading role that caregivers perform and the potential they have to exert widespread influence on early intervention for effective improvement on speech and language of their children.

The independent variable is the involvement of caregivers of children with speech and language disorders. The positive engagement of caregivers play a significant role in ensuring that children with speech and language disorders benefit from intervention services both at clinic and home services. The dependent variable is intervention programs for children with speech and language disorders in rehabilitation clinics. Its success (improved speech/language disorders) and support is determined by the extent of caregivers' involvement in early intervention. It is expected that the involvement of caregivers to a great extent in early intervention programs, enhance the efficacy of intervention services in terms of improved speech and language among children.

The economic status (the ability to afford the cost of therapy) and educational background (knowledge of disorders and therapy process) of caregivers of children with speech and/or language disorders greatly influenced their perceptions and involvement in early intervention programs as a greater

percentage reported financial constraints as a barrier and need for training. Depending on the cultural and environmental situations, the caregivers' gender influences their perceptions and involvement in early intervention programs for their children with speech and language disorders. The intervening variables included caregivers' economic status, educational background and cultural beliefs which confounded the effect of the independent variable, on the dependent variable, thus magnifying the effect.

1.7. Operational Definition of Terms

Caregiver refers to parents and guardians of the children with communication disorders who take care of the needs of the children with speech and language disorders (ASHA, 1993).

Communication used to mean any substantial exchange of information via an agreed channel between individuals (ASHA, 1993).

Intervention Programs in speech and language pathology referred to development of services provided for individuals with communication disorders (CDI, 2010).

Language disorders refer to impairments in using spoken system that includes language forms (grammar and phonology), the content (semantics) as well as the function-pragmatics (ASHA, 1993).

Involvement refers to the shared responsibility for activities planned and linked to speech and language improvement goals by engaging caregivers of

children with disorders in early intervention services as integral partners (ASHA, 1993).

Speech disorders refer to impairment in the articulation of speech sounds, fluency, and voice (ASHA, 1993).

Speech-Language Disorders refers to communication disorders that are typically categorised by their impact on a child's ability to communicate such as receptive skills (comprehension) and expressive skills in terms of sound articulation, appropriate use of rate and rhythm during speech, as well as appropriate vocal tone and resonance, and use sounds, words, and sentences in meaningful contexts (ASHA, 1993).

CHAPTER TWO

REVIEW OF RELATED LITERATURE

2.1. Introduction

This Chapter reviews previous studies works relating to the study. It provides a summary of the relevant literature used in the study. The Chapter also discusses the major concepts and theories relating to the study by examining existing materials on the historical background of special educational needs and assessment centres for children with special educational needs. Related studies on assessment centres and critiques of theories on special educational needs have also been discussed under this section.

2.2. Caregivers' Awareness of Speech and Language Disorders

Intervention process

One of the major obstacles to caregivers' involvement and adherence to treatment is ignorance about the nature of the disorder, the treatments and how effective these can be. Corlett, (1996) suggests that caregiver's knowledge about the disease is one of the primary reasons for medication non-adherence, while administration of medicine and failing to appreciate the vital role of drugs in treatment in the disease management is also another reason. Increased knowledge and health awareness among patients/caregivers on the condition of their disease helps in making informed decisions concerning health needs. Patients/caregivers non-adherence to treatment appointments may be attributed

to lack or insufficient knowledge about treatment or how the treatments work (Bultman & Svarstad, 2002).

Caregiver involvement, aim at developing caregiver skills to manage their caregiving activities in order to minimize their burden. The obvious assumption in intervening is that by minimizing caregiver burden and improving their skills, the child will also benefit. Information and education, about communication disorders that focus at raising awareness, improving understanding as well as minimizing stigmatizing attitudes among caregivers will help overcome barriers to accessing and using early intervention services. Information needs to include understanding the characteristics, cause and course of the disorder and what services are available to families, along with training in how to help their children (Griffin et al., 2013).

Patients are likely to adhere to treatment procedures when they understand interventions and how these interventions lead to improved health (Levers et al., 1999). Since caregivers' knowledge and awareness of the disorder is crucial for effective involvement, the current study will explore trainings and awareness creation as one of the involvement levels. Some caregivers lack knowledge on the role they play in the treatment; others lack knowledge about the disorder and consequences of poor compliance (Alm-Roijer, Stagmo, & Uden 2004); or lack understanding of the value of clinic visits. Training caregivers impacts positively on children in intervention and even after the transition from the interventions (Adams & Lloyd, 2007; Roberts & Kaiser,

2012). Children are likely to generalise new skills learnt in therapy if caregivers are trained to implement them at home and influences positive perception toward early intervention efficacy.

Morris and Stein (2005) conducted a study on steps to enable more people to access speech and language therapy in Haringey, North London. They carried a survey on both caregivers attending and those not attending appointments. They found that caregivers (parents) generally had limited knowledge about speech and language therapy and how it could benefit their child. Lack of caregiver's knowledge of speech and language development and treatment may be a barrier for engagement in the services as well as a determinant to caregivers' perceptions on early intervention efficacy. Likewise, Glogowska and Campbell (2000) noted that some parents had limited knowledge about speech and language services and approach it with anxiety, though it can be resolved by provision of information and support from speech and language pathologists. Lyons et al., (2010) also noted that it is crucial for caregivers and therapists to construct a substantial shared opinion of the intervention process.

In some occasions, some caregivers lack understanding of the role they play in the intervention process and the value of clinic visits. Others lack knowledge about the condition and the implication of non-compliance (Alm-Roijer et al., 2004). Therefore, building the capacity of caregivers on the need for, and value of, early speech and language therapy is important for promoting attendance as well as positive involvement in early intervention. The current study therefore

was to find out the steps put in place to capacity build caregivers for effective early intervention program in Bomet County.

2.3. Caregivers Involvement in Intervention for Children with Speech and Language Disorders.

Early intervention services are crucial for caregivers and familiar context of children with speech-language disorders. Caregivers and families members of these children experience social isolation, emotional turmoil and difficulties of managing their children. These family dynamics are affected to the extent of compounding the child's disorders thus influencing their perceptions and active involvement in early intervention programs. Therefore, caregivers and family members ought to take the centre stage for the intervention of children with speech-language disorders (Girolametto et al, 2001).

Early experiences in life are vital in organizing the brain's basic structures, as they create the neural foundation for all subsequent development and behaviour (Greenough, 1993). Lack of stimulation leads to cell death in a process called "pruning" hence eliminates pathways that are not used (Greenough, 1993). The current study benefited from this literature in ensuring that caregivers were made aware of the benefits of early intervention before any form of involvement.

The child's early life experience is dependent on interpersonal interactions. According to neurobiological research, the child's readiness for formal learning and potential for the intellectual development, emotional balance, and social

skills are dependent on the quality and quantity of interaction with the caregivers (Shonkoff & Hauser-Cram, 1987). Understanding the importance of early language stimulation among caregivers enhances involvement especially in home-based intervention programs.

McCain, Mustard and Shanker, (2007), advocate for effective early interventions that is integrated, in a multi-disciplinary and intersectoral programs to enhance caregivers' involvement. Early intervention depends on the earliest and substantive identification of speech and language disorders which is determined by caregivers' involvement and perception on the importance of early intervention. Therefore lack of intervention, results to a slower rate language development among children compared to their normally developing peers, and some developmental milestones are not attained until much later than normal or not completely (Fey, 1986).

Caregiver's involvement in early intervention program commence with the clearing up the myths about the disorder, as well as psychosocial support to overcome challenges. They are subsequently educated about the implications and crucial interventions so as make vital decisions about the child's treatment. Girolametto, Weitzman and Greenberg, (2003) in their exploratory study about the outcome of in-service training of caregivers of a day care centres, engaged sixteen caregivers as experimental and control groups. The result supported the viability of training caregivers for effective early intervention.

Ultimately, the caregivers should be equipped with knowledge and skills necessary to support the intervention process that helps to influence positive perception on early intervention efficacy. Substantial efforts caregivers' empowerment will result in caregivers improved attitudes between themselves and their children, as well as being capacitated to train their children (Baxendale & Hesketh, 2003; Tanock & Girolametto, 1992). Interventions designed to help the caregivers to become more competent and confident in provision of therapy are vital in ensuring that their children receives effective therapy. These interventions help preventing neglect and improve the caregiver's knowledge and skills and support caregivers with early identification of child problems and managing child care.

Caregivers' involvement is critical since they are more informed, of the abilities and limitations since they spend more time with their children and interacts more frequently informally. They are also willing to spend their resources for the well-being of their child (Girolametto et al, 2001; Girolametto & Weitzman, 2006; CDI, 2010). Besides caregivers involvement benefits for themselves, they also influence the early intervention services for their children with speech and language disorders. Evidence has shown that the knowledge and attitudes of caregivers towards their children's communication are clear indicators of their contribution to their children's early intervention and progress (Stephens & Slavin, 1992). It involves the extension of therapy and monitoring learning at home, constant and consistent interaction with the therapists, and participation in capacity building programs (Epstein, 1987;

Yathiraj, 1994). Given that caregivers are integral participants in rehabilitation process, the current study sought to establish the levels at which caregivers are involved in early intervention program in Bomet County.

Caregiver's active involvement is considered vital for effective intervention (Granlund, Björck-Åkesson, Wilder & Ylven, 2008; Marshall & Goldbart, 2008; Sen & Goldbart, 2005). In their review of randomised studies (1996-2009) to establish if individual type of intervention are more effective than others in improving the speech intelligibility of children with dysarthria, Pennington, Miller and Robson, (2010) found that intervention program that targets the family context to increase interaction opportunities could be effective. It is expected that the family focus will not only benefit the child alone but also family dynamics and interaction (Granlund, Björck-Åkesson, Wilder & Ylven, 2008).

The participation of caregivers in interventions that focus on the child based on relationship in the home setting has been reported to: improve child development, promote language growth (Roberts & Kaiser, 2012), alleviate negative interactions between the child and caregivers (McIntyre & Abbeduto, 2008), lower levels of caregiver stress and improve family outcomes (Kim & Mahoney, 2005). Effective caregivers involvement therefore can be achieved through different levels: Appointments and decision making (Bultman & Svarstad, 2002); Capacity building and Psycho-social support (Adams & Lloyd, 2007; Roberts & Kaiser, 2012).

Caregivers are effectively involved by adherence to appointments. According to Kolt & McEvoy, (2007), caregivers involvement include; attending appointments to therapy, following advice on treatment, undertaking prescribed home programs, following the frequency of prescribed appointments as advised and caregivers' participation on treatment. The relationship between the doctor and the patient has been shown to be strongly associated with appointment adherence (Bultman & Svarstad, 2002). Good caregivers-therapist relationship can contribute to improved appointment adherence and in turn effective involvement. The therapist-patient relationship seems to be an important factor for caregivers' involvement, which includes the process of inquiry for diagnosis, decision making, examination, prescription, and interaction. Poor communication between the therapist and caregivers during this process may affect the level of appointment adherence as well as involvement. The current study therefore sought to determine the level of caregivers' involvement in decision making and appointments to therapy in Bomet County.

In their quantitative study, Johnson & Hasting, (2002) engaged 141 UK parents in questionnaire on home-based behaviour intervention. They found that stress was psychological and that the low level of stress was associated with effective intervention and high level led to caregivers' pessimism. Psychological support is an integral part of the intervention particularly at home and has been reported to be a crucial motivating factor by parents implementing a behavioural intervention with their children with autistic spectrum conditions (Johnson & Hastings, 2002). Parent-directed training intervention strategy,

whereby improvement in the child's communication skills is achieved when parents acquire information and adopt new ways of communicating with their children.

According to Johnson & Hastings, (2002) patients who are supported emotionally and helped by family members and clinicians are more likely to comply with the treatment procedures. The psychosocial support helps caregivers to reduce negative feelings towards treatment, being motivated hence remember to implement the treatment. The current study sought to establish the effect of psycho-social support on caregivers' adherence to treatment procedures in an early intervention program, Tenwek Hospital.

Caregiver empowerment is an integral component of an intervention process for children with speech and language disorders. Knowledge and skills transfer as well as attitudes molding is enhanced through regular counseling sessions and guidance, organization of frequent seminars, workshops and conducting formal training programmes. These measures equip caregivers for effective home training and participation in therapy activities, which in turn enhances improved communication of their children. Furthermore, other family factors such as socio-economic status of the caregivers, education and family size are found to exert substantial influence on the extent to which family members are involved in the intervention process (Malar, Sreedevi & Suresh, 2013).

Previous studies have cited the FOCUS program which includes a supportive education intervention that targets family involvement, an optimistic attitude,

coping effectiveness, reduction of uncertainty, as well as symptom management to be effective in intervention process (Griffin et al., 2013). Family caregivers can be involved in providing therapy or also in organizing for therapy delivered by others. Such interventions that actively involved families improve their psychological well-being, depression and disorders management skills (Griffin et al., 2013).

Building caregivers' competence and confidence improves their mastery in therapy procedures, higher levels of caregivers 'mastery of the intervention process bear more positive responses to the provision therapy since they perceive themselves as being able to meet intervention demands (Cameron et al., 2006). Lower stress and more positive confidence in therapy are attributed to caregivers' mastery of intervention procedures. Research indicates that caregivers with confidence and who feel prepared to take therapy tasks have less stress (Scherbring, 2002).

According to Scherbring, 2002, caregivers require knowledge, and skills to carry out the tasks intervention which takes into account the various dimensions such as the nature of the tasks, performance frequency, the time limit for care provision each day, the caregivers' skills, knowledge, and abilities to perform tasks, the extent to which routine can be achieved, thus task be incorporated into daily schedules, and the guaranteed support from other family members. Different involvement strategies demands different skills and knowledge, organizational capacities that require social and psychological strengths from caregivers.

A problem-solving training and therapy caregiver model summarized as COPE (Creativity, Optimism, Planning, and Expert information) was designed to empower family members to moderate caregiver stress, trains caregivers to design and carry out plans that focus on therapy and psychosocial problems (Houts et al., 1996).

Pennington, Thomson, James, Martin, and McNally, (2009) investigated whether It Takes Two to Talk—The Hanen Program is associated with change in the patterns of interaction between children with motor disorders and their parents. They used 11 children between age one and three and their mothers were involved and used a quasi-experimental design. They found that the training equipped caregivers to become more responsive and less directive with children to gain more control in the interaction. Promoting caregivers inclusive intervention programs is critical for any effective early intervention.

Caregivers' viable interactions with their children, in more natural and habitual environment, increase their emotional attachment. This interaction is fulfilled by trying to balance turn-taking with the child, being non-directive, make activities enjoyable, minimize stress, avoid negative judgments, and focus on keeping the interaction going (MacDonald & Carroll, 1992). Every interpersonal contact provides an opportunity for active engagement in communicative contexts which build natural and therapeutic relationships between caregivers and the child (MacDonald & Carroll, 1992).

Clinician need to create effective mode of communication with caregivers to develop cost-effective plans disorder management and achieve positive client outcomes Dalton, 2005. According to Dalton, caregivers find difficulties obtaining information from health care professionals. It is important to provide mutual respectful communication and clear information in a manner that caregivers understand verbally, electronically and by writing.

Caregivers need information concerning the condition of their child and intervention procedures, time to have their questions answered. Clear information relieves caregivers' depression arising from uncertainties about their child condition and appropriate intervention (Given & Given, 1996). Substantial communication and caregiver support by training on new skills improves their competency thus enhances effective involvement. Therapist play vital role in helping caregivers to gain confidence and competence to engage in an intervention process.

2.4. Barriers to Caregivers' Involvement in Early Intervention for Children with Speech and Language Disorders.

There are several potential barriers to caregivers' involvement. Lack of training and information on caregivers' involvement may translate to their relatively lower levels of involvement (Lazar, Broderick, Mastrilli, & Slostad, 1999). These barriers may include negative attitudes to diagnosis and treatment, lack of appropriately trained health professionals, low help seeking due to culture

influence or stigma, lack functional public policy initiatives, and lack of funds therapy services, research, and training. In many low- and middle-income countries such as Kenya, no support services are routinely available for family caregivers of children with communication disorders (McCartney, 1999).

Lack of recognition of the caregiving role by clinicians, poor understanding of disorders and cultural influences on caregiving is also a critical concern in early intervention services. Caregiver often feels unprepared to provide care, due to inadequate knowledge to deliver proper care and often receives little guidance from the therapists (Schumacher et al., 2000). Equally, there may be language barriers or a lack of understanding when it comes to the significance of therapist-caregivers communication.

Caregivers often neglect their role in an intervention process simply due to inadequate knowledge and skill. They may be unfamiliar with the strategy and type of care they need to provide or the extent of their involvement as well as resources available for intervention process. The need to make decisions on behalf of their children is stressful, as they are concerned that the decisions are correct (Schumacher et al., 2000).

Caregivers' inconsistent involvement is attributed to various variables. Previous studies have found that caregivers of children with communication disorders experience varying levels of stress, depression, different socio-economic levels which have an impact on their availability to engagement in

intervention process (Benson, Karlof, & Superstein, 2008). Job and other commitments is one the major barriers to caregivers involvement. Caregivers, who try to strike a balance between caregiving and other obligations like family attention and work, may find challenges in devoting their efforts positively on intervention process resulting to distress (Stephens et al., 2001). Caregivers may be distressed even more if they fail to participate in valued activities. These have negative effect on their activities they as try to cope with employment obligations to manage and meet intervention demands. Research indicates stress as a major contributor to lack of parental involvement in early intervention program for their children. Limited time and energy, socio-economic status, other children to care for; employment commitments and lack of support has been cited to contribute to lack of caregivers' involvement (Benson, et al., 2008).

Therapist-Caregiver interaction may be a barrier to active participation and utilization of intervention services in many communities. In their study, Sharkawy, Newton and Hartley (2006) in Kenya found that caregivers of children with epilepsy who had unpleasant experiences with clinicians in health care facilities terminated their child treatment programmes. Regular interaction by the caregivers and the therapist boosts health relationship viable for effective involvement. Adherence to treatment seems to relate with quality, duration as well as interaction frequency between the patient and doctor. The clinician's attitude towards the client and the ability to elicit and respect the concerns of the client, and appropriate provision of information as well as

demonstration of empathy is of the utmost significance (DiMatteo, 1994). Social and economic factors include: time commitment, cost of therapy, income and social support.

Ndung'u and Kinyua, (2007) conducted a survey to establish the cultural perspective that play a role in determining the interpretations of language and speech disorders and their subsequent management in Kenya. They interviewed twenty persons aged 20 to 53 years during Operation Smile, Kenya Chapter Mission. They found that cultural differences play a key role in various communities and may determine whether caregivers of those with communication disorders will be involved in early intervention or not and the extent of their involvement.

In many instances, those who have a belief that a given disorder is a curse from God may not wish to offend God more by seeking clinical attention. Children whose parents have such beliefs fail to or seek treatment too late, when treatment may not be effective as it would have been if early intervention occurred. Various disorders such as stammering are attributed to different beliefs like stammering if one speaks in English, play with chameleons or laughing at a stammers among Agikuyu community in Kenya. These beliefs make it so challenging for any early intervention services to be initiated.

Ndung'u and Kinyua, (2007) argue that delay or lack of intervention is evident in many Kenyan communities where various communication disorders, such as

stammering, are presumed to have been caused by evil spirits or curses by the ancestors. To achieve effective treatment of these disorders, the speech pathologists need to understand the cultural perspectives of the caregivers and commence by building the capacity of caregivers to understand the disorders through a training program or clear explanation. The current study sought to establish ways in which cultural differences could be incorporated into intervention programs through caregivers' involvement in Tenwek Hospital.

Family conflict is also a barrier to caregiver's involvement since there is little help to the patient. Previous studies found out that disagreement between primary and secondary caregivers results to negative effects on the patient's improvement (Bourgeois, Beach & Burgio, 1996). The current study benefited from this literature by establishing the extent to which these factors hindered caregivers' involvement for effective early intervention in Tenwek Hospital, Bomet County.

2.5. Caregivers' Needs for Involvement in Intervention Program for Children with Speech and Language Disorders.

Ongoing caregiver involvement is crucial for planning and implementation of an intervention program for children with speech and language disorders. Observational data from a caregiver on the child's pattern of behaviour from infancy to childhood provide useful information for intervention plan. Caregivers are also involved in decision making for their child's early

intervention program, attending workshops on specific strategies, participating in parent support groups, engaging in therapeutic activities, participation in team meetings and communication such as communication notebooks, newsletters or written materials (Kolt & McEvoy, 2007).

Identification of the needs of patients and their caregivers is the basis for the development of interventions sensitive to these needs, education and counseling on the condition and treatment strategies. Previous research has shown that most unmet needs relates to lack of knowledge about the existing services, progression and management of the condition (Brodaty, Thomson, Thompson & Fine, 2005). An educated caregiver may serve a vital role as a resource person in recognizing patient's needs, routines, and manifestations of disorder. Therefore, training caregivers not only reduce their distress but also employ their knowledge acquired for earlier detection and treatment of their child's disorder (Miller et al., 2004).

Therapists need to identify caregivers' strengths and help them to build their confidence and awareness of the assets they have for intervention process. This will acknowledge their ability to support their children. Identifying strengths is crucial because it builds patients' and caregivers' self-efficacy, since research has found that higher self-efficacy is related to many positive outcomes for both patients and caregivers, including (Kershaw et al., 2008).

For early intervention programs to be successful and improvement in communication skills to be noted in the child, the caregivers need to be engaged. Marshall & Goldbart, (2008) conducted a qualitative study in Britain to explore the experience of parents of children with communication disorders using Augmentative Alternative Communication (AAC) and the impact on family life. They interviewed eleven parents (caregivers) and found that parents are experts in their children and speech therapists should acknowledge their vital role in intervention process. Marshall & Goldbart, (2008), study supports the vital role caregivers play in the achievement of early intervention goals and success for the children. However, therapists do not take into consideration of the wants and needs of caregivers in the involvement process.

Comprehensive counselling sessions for caregivers may help reduce stress improve the quality of life for caregivers of children with communication disorders. Studies have found that even a telephone call have a far reaching effect in supporting the caregiver psychosocial well-being. An automated telephone system that provides an interactive voice-response supports caregivers in reducing stress for those caregivers who had no control over their situation. Previous studies have compared an in-home and telephone-based skill training interventions among caregivers of persons with dementia. The findings reveals a substantial reduction in burden and minimal distress for caregivers who receives friendly and socially supportive phone calls that provided some respite from caregiving, even without home-based caregiver skills training (Davis et al., 2004). The current study therefore sought to

investigate caregivers' needs for involvement in early intervention program for children with speech and language disorders in Tenwek Hospital, Bomet County.

2.6. Summary Literature Review

Reviewed literature focuses on the role of caregivers in early intervention of young children. According to Morris & Stein (2005), ignorance about the nature of the disorder, the treatments and how effective it can be is the major obstacles to caregivers' involvement and adherence to treatment. Caregiver's knowledge about the disease is one of the primary reasons for medication non-adherence, hence compounding the children's disorders (Bultman & Svarstad, 2002). The reviewed literature confirms the importance of caregivers' knowledge of the disorders and the treatment procedures. The current study was to establish caregivers' awareness of the disorder and treatment procedures for children with speech and language disorders.

Pennington, Miller and Robson, (2010) review of randomised studies (1996-2009), reveals the success of intervention programs and improvement on the child when parents are involved; however it is not clear the extent to which caregivers are involved. The current research therefore sought to establish the extent to which caregivers are involved in early intervention programs and its effects on the child.

Caregivers' involvement is considered to be a critical component in the success of early Intervention programs, yet there is limited information on the factors that play a role in caregivers' involvement (Ndung'u & Kinyua, 2007). The current study was to find out the barriers to caregivers' involvement in intervention for children with speech and language disorders in Tenwek Hospital, Bomet County

There is a gap in the literature with regards to the needs of caregivers for them to be engaged in a rehabilitation process. Literature has shown the success of programs when caregivers are involved (Marshall & Goldbart, 2008). Caregivers are expected to take part in the intervention process without consideration of their wants and needs. However, there is limited research on caregivers' needs for successful involvement in early intervention programs. The current study sought to investigate caregivers' needs for involvement in early intervention program for children with speech and language disorders in Tenwek Hospital, Bomet County.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

This Chapter discusses the methodology that will be used in this study. It explain how the research will be conducted, survey methods and data analysis. It describes the research design, variables, the study population, sampling technique, sample size, instruments, piloting, validity, reliability, data collection, data analysis, logistical and ethical consideration.

3.2 Research Design

The study adopted a case study design which employs both quantitative and qualitative approaches (Creswell, 2003). The design was chosen because it has the advantage of producing good responses from a particular locale. It suited the current study which was carried out in one hospital. It ensures objective and accurate data collection to describe an existing phenomenon.

3.3. Variables

3.3.1 The independent variable of the study is caregivers' involvement.

3.3.2 The dependent variable is intervention programs for children with speech and language disorders.

3.3.3 Intervening variables include; education, economic status, and cultural beliefs.

3.4 Location of the Study

This study was conducted in Tenwek Mission Hospital Bomet County of Kenya. Tenwek Hospital is located near the town of Bomet, approximately 240 kilometres northwest of Nairobi. The inhabitants of Bomet County practice farming and business activities. The hospital was selected because it has an outpatient rehabilitation clinic that caters for children with speech and language disorders in the County and the surrounding Counties. Therefore, caregivers and therapist (target population) converge in the hospital clinic for therapy and training.

3.5 Target Population

The current study was carried out in Tenwek Mission Hospital, Bomet County. Caregivers of children with speech/language disorders (all ages 2-15 years), Speech and Language Pathologist (SLP) and Physiotherapist (PT) formed the accessible population. Available records in Tenwek Hospital showed that in the year 2015, a total of 60 children from 60 families were diagnosed and attended to. Further, there are two therapists (SLP & PT) dealing with children rehabilitation in the Hospital adding to a total of 62 respondents.

3.6 Sampling Techniques and Sample Size

3.6.1 Sampling Techniques

The current study employed purposive sampling technique and utilised all the accessible population (Kombo & Tromp, 2006). According to the clinical reports in Tenwek Mission Hospital records, 2015, diagnoses included autism, pervasive developmental disorder, cerebral palsy, and other developmental disabilities associated with speech and language disorders. The study therefore purposely utilised only all caregivers whose children were identified with speech and language disorders as per the Tenwek hospital rehabilitation clinic records.

3.6.2 Sample Size

The sample size consisted of a total of sixty (60) caregivers and two therapists. The total sample comprised 62 respondents.

Table 3.1 Sample Size

Sample size categories	Target Population	Sampled Size (Utilised all accessible Population)
Caregivers	60	60
Therapist: SLP/OT	2	2
Total	62	62

Source: Tenwek Mission Hospital Records (2016)

3.7. Research Instruments

Two data collection instruments used to collect the data from the respondents included a structured questionnaire and an interview guide. The items in the research instruments were constructed by the researcher with the help of the expert supervisors based on the study objectives.

3.7.1 Questionnaire

The questionnaire contained both structured (closed-ended) and unstructured (open-ended) items. The questionnaires consisted of a list of questions relating to the objectives and research questions of the study. They were administered directly to the respondents and collected on the same day for a period of two months. Open and closed-ended questions were used to elicit qualitative and quantitative information respectively from the caregivers. The questionnaire sought to gather information regarding the following:

- Demographic information of caregivers
- Caregivers' awareness of speech and language disorders intervention process
- Levels of caregivers' involvement programs
- Barriers to their involvement in intervention program
- Needs for involvement in intervention program.

The questionnaire contained closed-ended items on a five-point Likert-type scale of; Never, Rarely, Sometimes, Very, Always. Never coded as "0" imply

no involvement in intervention program while Always coded as “4” implying highest level of involvement in intervention program.

The open-ended questions allowed the respondent more freedom of response, experience and views on the caregivers’ involvement in early intervention programs.

3.7.2 Interview guide

An interview guide was administered on the therapists since it allows probing and appropriate to a small population. The interview guide was employed to help the researcher elicit verbal responses from the therapist. Use of interviews helped the researcher to probe the respondents and therefore get more in-depth information. Interview guides were used to elicit information concerning;

- the extent of caregivers’ involvement in early intervention for children with speech and language disorders in Tenwek Hospital, Bomet County,
- Barriers to caregivers’ involvement in early intervention for children with speech and language disorders,
- Caregivers’ needs for involvement in early intervention program for children with speech and language disorders in Tenwek Hospital.

The questions on the interview guide with a set of probable responses were supplied and the responses from the therapists recorded appropriately.

3.7.3 Piloting

A pilot Study entails a small-scale testing of the procedures that the researcher planned to use in the study. The aim was to check on the clarity of the questionnaire items and instructions and to eliminate ambiguity in wording. The other reason was to check on time taken to answer questions and complete the questionnaires. The pilot study was conducted at Vihiga referral hospital in Vihiga County. The location was chosen because it is the only nearby hospital that offers similar outpatient rehabilitation services as Tenwek outpatient clinic in the western region. The pilot study used 10% of the study population who are the main respondents (Neumann, 2006). Six caregivers who bring their children with speech and language disorders to Vihiga hospital for rehabilitation (randomly selected) and one therapist (purposely selected) formed the sample size for piloting.

3.7.4. Validity of the Instruments

Validity is the extent to which an indicator accurately measures a concept (Ary, Jacobs & Razavieh, 2002). In the case of the present study, expert judgements were used to determine the content or face validity of the items on the questionnaires and an interview guide. In determining the face validity of the instruments, two course supervisors from the Department of Special Needs Education and professional lecturers in the School of Education at Kenyatta University verified the content validity of the instruments.

3.7.5. Reliability of instruments

Reliability refers to the extent to which a measure would earn consistent results each time it is used (Ary, et al., 2002). After the construction of the research instruments, a pilot testing to discover likely weaknesses, inadequacies, ambiguities and problems in the items on the questionnaire was carried out and corrected before the actual data collection exercise. A reliability test was performed using Cronbach's Alpha to establish the internal consistency of the items on the questionnaire. A reliability coefficient of 0.7 and above was acceptable (Fraenkel & Wallen, 2000). Such a reliability coefficient is considered to be sufficient to confirm and reflect the internal consistency of the instruments.

After piloting the data collection instruments, the internal consistency procedure was used to determine the true score variance in the characteristics measured by the instruments. This was determined from the score obtained from a test administered to a sample of subjects. Therefore all the data collection tools used in this study were accurate hence suitable for the study. The Cronbach's Alpha reliability coefficient value for this instrument was 0.721. Table 3.2 below shows a summary of the reliability tests obtained.

Table 3.2 Reliability Tests

Variables items	Cronbach's Alpha	No. of
Level of involvement	0.721	7

Source: Researcher (2017)

3.8. Data Collection

Permission was sought to conduct the research from the National Council of Science and Technology, through the Director, Graduate School Kenyatta University. A letter of introduction from the Graduate School, Kenyatta University and a personal letter of information to the head of Tenwek Mission Hospital in Bomet County. The data collection was carried out in two phases spanning for two months. Phase I, which involved distribution and collection of the questionnaire, took two months to complete. Phase II entailed conducting of Interviews for SLP and PT and was done in the last week of the two months. Data from the interviews was recorded manually (paraphrased) and Audio-recorded respectively.

3.9 Data Analysis

The collected data was coded, classified, organised and summarized according to stated objectives and research questions. It was then summed up for every individual variable. Descriptive statistics in the form of frequency counts, percentages and tables was used to organize, summarise, interpret and

communicate quantitative data or describe the characteristics of the sample population on caregivers' awareness, involvement level, barriers to involvement and caregivers' needs for involvement in intervention program. Qualitative data derived from the interviews, objective one and four was coded in the basis of themes and analysed thematically. Recorded data was organised and then transcribed to make an overall sense of data. Quantitative data was analysed into frequencies counts, tables, percentages, graphs and pie charts with the aid of Statistics Package for Social Sciences (SPSS) computer programme for windows.

3.10 Logistical and Ethical Considerations

Consent was obtained from relevant authorities before proceeding with the pilot study in Vihiga County. Upon a successful pilot study, the researcher proceeded to the location of the study in Tenwek mission hospital for the main study with the permission from relevant authorities. Respondents were assured that their responses would be kept confidential. Questionnaires were filled confidentially and handled over directly to the researcher. They were also assured that findings of the study would be shared with them upon completion of the research.

CHAPTER FOUR:
PRESENTATION OF FINDINGS, INTERPRETATION AND
DISCUSSION

4.1 Introduction

This Chapter presents the results of the data collected, analysis and discussion of the implication of the data. The study was designed to assess caregivers' involvement for effective early intervention for children with speech and language disorders in Tenwek hospital Bomet County. The chapter captures the demographic profile of respondents and objectives of the study using frequency tables and percentages as presented below:

- i. Investigate the caregivers' awareness of speech and language disorders intervention process in Tenwek Hospital, Bomet County.
- ii. Establish the extent of caregivers' involvement in intervention program for children with speech and language disorders in Tenwek Hospital, Bomet County.
- iii. Find out the barriers to caregivers' involvement in intervention program for children with speech and language disorders in Tenwek Hospital, Bomet County.
- iv. Investigate caregivers' needs for involvement in intervention program for children with speech and language disorders in Tenwek Hospital.

The distributed questionnaires were 60 targeting caregivers involved for early intervention for children with speech and language disorders in Tenwek hospital, Bomet County, Kenya. The questionnaires that were properly filled and collected are 52. This amounted to 86.7% of the total respondents, which was adequate to make the analysis and discussions. The rate of response based on gender is summarized as shown in Table 4.1

Table 4.1 Questionnaire Return Rate

Gender	Frequency			Percentage
	Rural	Urban	Total	
Male	6	1	7	13.5
Female	44	1	45	86.5
Total	50	2	52	100

From the results in table 4.1, it is clear majority of the respondents filled the questionnaires satisfactorily as required. However, some of the respondents were reluctant to participate due to the sensitivity of the topic under investigation. Furthermore, some respondents were not conversant with the rehabilitation process and rarely attended therapy appointments. Nevertheless, the researcher managed to get substantial number of respondents to fill the questionnaires.

4.2 Demographic Characteristics of the Respondents

In terms of gender, among the 52 respondents who responded positively to the questionnaires, more than three quarters were female and male representing less than a quarter of the respondents. The table below gives the summary of the respondents' demographics by gender.

Table 4.2 Respondents by Gender

Gender	Frequency			Percentage
	Rural	Urban	Total	
Male	6	1	7	13.5
Female	44	1	45	86.5
Total	50	2	52	100

Table 4.2 above clearly indicates that the majority of the respondents were females as opposed to males. It was hoped that this gender disparity did not have any bearing on involvement in early intervention for children with speech and language disorders. Nevertheless, it was clear that majority caregivers who brought their children for therapy sessions were female probably due to cultural influence that bestow the responsibility of child rehabilitation to the female which has an implication on familiar social and physical support. Majority of the respondents resided in rural setting implying that they were either housewives or self-employed.

Numbers of Siblings

The figure below highlights the research findings on the number of other siblings in the family that depends on the caregiver who participated in the study.

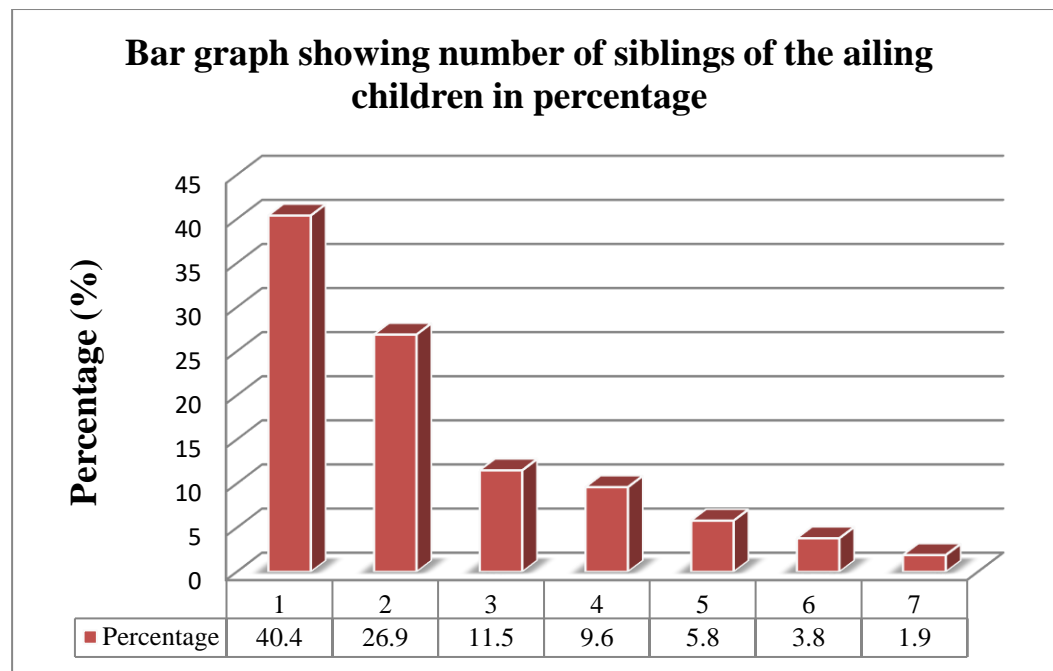


Figure 4.1 Numbers of Siblings

With regard to the number of siblings, the table above shows that nearly half of the respondents indicated that the family had two siblings with about a quarter of them reporting to have one sibling. Less than a quarter of the respondent confirmed the family having three siblings with almost the same number of them reporting to have none. Those with four siblings were very minimal with two respondent reporting to have six siblings and one confirmed to five siblings 1.9% respectively. The result indicates that majority of the respondent

had at least 1 other child to care for apart from the one with speech and language disorder. This had an implication on the involvement in intervention programs due divided responsibility thus a hindrance to substantial involvement. The findings are in line with the previous studies that found other children to care for in a family to be a barrier on involvement (Benson, et al., 2008)

In terms of caregivers' level of education, the researcher sought to find out the highest education level of the respondents because this could influence the level of the caregiver's involvement in intervention programs for children with speech and language disorders. The results are presented in Figure 4.2 below.

Highest Education Level of Caregivers

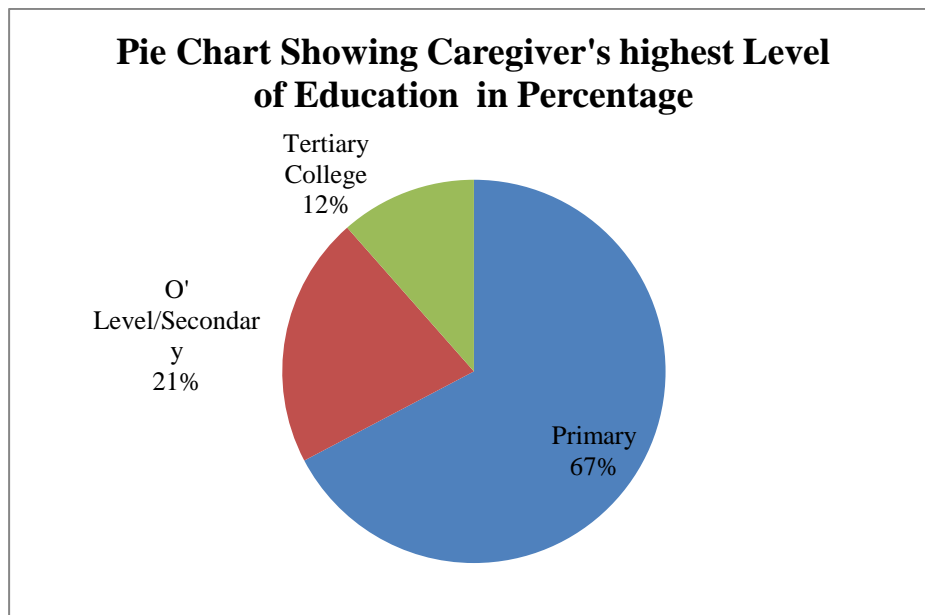


Figure 4.2 Highest Education Level of Caregivers

Figure 4.2 above shows the highest level of education of the respondents (caregivers) in Tenwek Mission hospital. Nearly three quarters of the respondents attained Primary Level. Almost a quarter of them qualified with O' Level with very minimal respondent reporting to have attained tertiary level qualification.

The information indicates that majority of the caregivers had low education level with very minimal having attained tertiary level. Therefore, though not a major barrier to effective involvement in early intervention process, it was hoped that the level of education could influence the level of involvement for effective early intervention process

Demographic Data on Child Accompaniment for Treatment

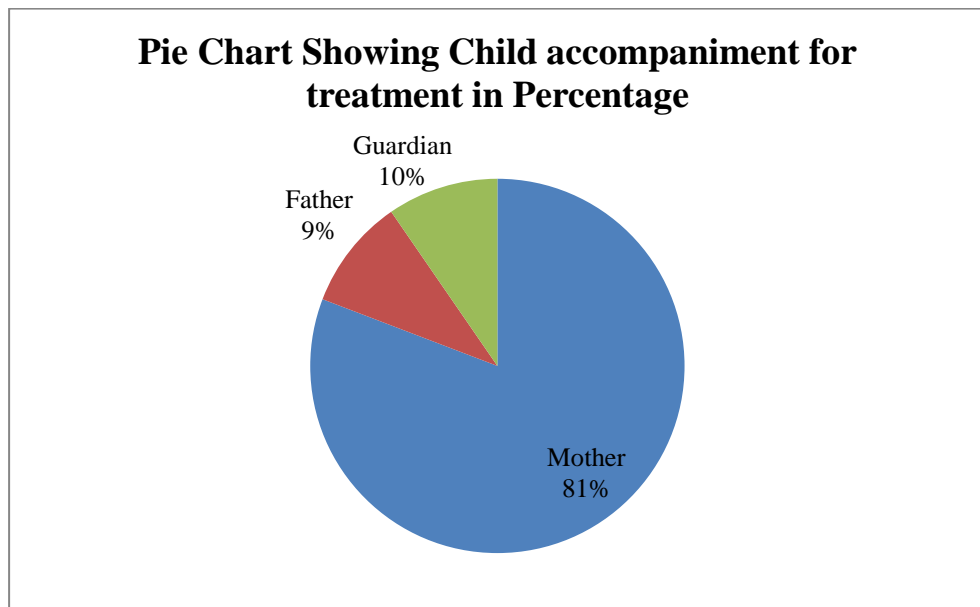


Figure 4.3 Demographic Data on Child Accompaniment for Treatment

The research sought to find out who accompanies the child to the clinic on regular basis. Figure 4.3 above shows that majority of the caregivers who accompanied the child to clinic were mothers. Rarely did the fathers accompany their children to the clinic. The results from Figure 4.3 also indicate that a significant number of guardians took the initiative to accompany the children to the clinic. The high rate of mothers who accompany their children as opposed to fathers signifies that the responsibility of child care has been bestowed on the mothers probably due to cultural influence which play a great role in most African family systems (Aspaas, 1998)

Employment Status of Caregiver

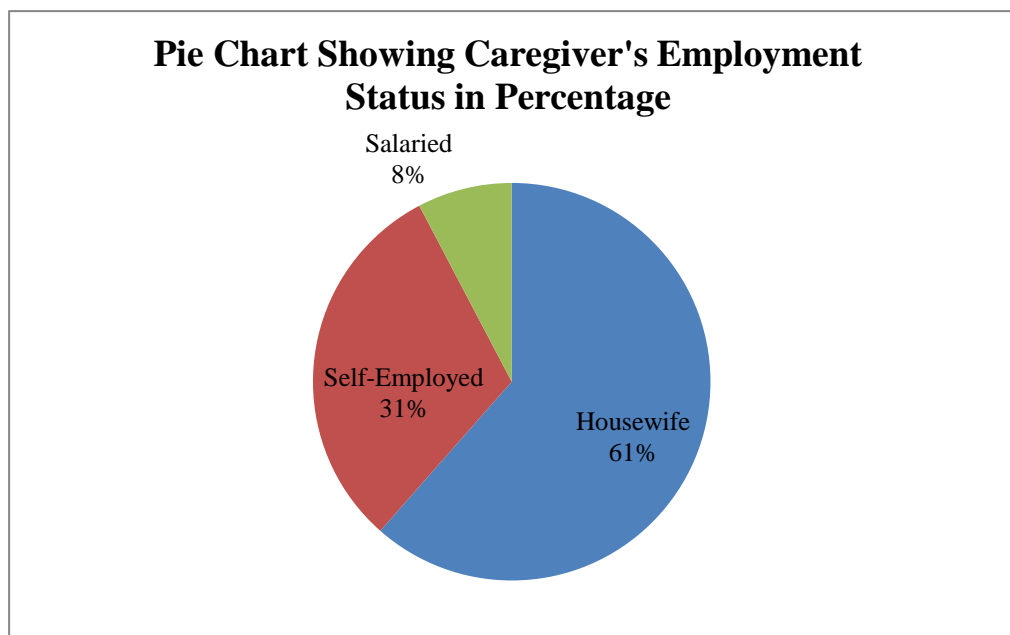


Figure 4.4 Employment Status of Caregiver

It is crucial to know whether employment status of caregivers could influence the level of their involvement for effective early intervention for children with

speech and language disorders. Figure 4.4 shows that slightly more than half of the respondents (caregivers) were Housewives. Significant number of caregivers reported that they were self-employed. Those reported to be engaged in formal employed and salaried were very minimal implying that majority depended on informal economic activity for a living.

The findings from Figure 4.4 indicate that majority of the caregivers hailed from low in-come families which could be a major barrier to effective involvement for early intervention process. Furthermore, it was hoped that majority could experience economic difficulties in terms of intervention costs. Nevertheless, the majority of the caregivers could have more time with their children and commitment to therapy sessions thus effective involvement.

4.3 Caregivers' Awareness of the Child Disorder

Objective one sought to find out caregivers' awareness of the child disorder which could influence the level of their involvement for effective early intervention for children with speech and language disorders. Open-ended items were designed to assess the respondents' (caregiver) awareness of the child's disorder (problem) and the cause of the disorder. Table 4.3 shows the frequencies and percentage responses on the caregivers' awareness of their child's speech and language disorder and the cause.

Table 4.3 Caregivers' Awareness of the Child Disorder

Category	case	Frequency	Percentage
Aware	Yes	30	57.7
	No	22	42.3
	Total	52	100.0
Problem/Concern	Unable to Communicate	9	30.0
	Unable to talk	6	20.0
	Unable to walk and speak	3	10.0
	Multiple disorders	10	33.3
	Cerebral Palsy (CP)	2	6.7
	Total	30	100.0
Cause	Don't know	18	60.0
	Prolonged Labor/Delayed Birth	12	40.0
	Total	30	100.0

Caregivers' knowledge and awareness about the disorder, its cause and ramification on the child as well as treatment is vital for effective involvement,

though some lack awareness on disorder, intervention process and consequences of non-compliance (Alm-Roijer, et al., 2004);

From Table 4.3, the information shows that among the 52 respondents, slightly more than a half of them responded to the items on awareness of the disorder of their children while almost a half of the respondents did not respond implying that they were either not aware or sensitive to the subject under investigation. The result indicates different description of their children's disorders. The respondents gave various descriptions about their understanding of the disorders as well as the cause. Slightly more than a third of the respondents reported that their children had multiple disorders while nearly two-third though used different terminology, they centered at their children having communication disorders. Only two of the respondent reported their children as having cerebral palsy condition. Despite a fact that majority of the caregivers were aware of their children disorders, nearly two-third of them confirmed that they were not conversant on the cause.

The findings of this study concur with Morris and Stein (2005) study on steps to enable more people to access speech and language therapy in Haringey, North London. They found that parents had limited knowledge about speech and language therapy and its significance. The current study likewise found that caregivers had not only limited knowledge of speech and language disorders but also the cause of the disorder. Lack of awareness of the disorder, cause and treatment procedures could be one of barriers for effective involvement. Capacity building of caregivers through trainings and provision

of elaborate information concerning speech and language disorders are matters of great importance to create awareness for effective involvement.

4.4 Level of Caregivers' Involvement in Intervention Program

Objective two sought to establish the the extent of caregivers' involvement in intervention for children with speech and language disorders in Tenwek Hospital, Bomet County. Both quantitative and qualitative data was collected from the caregivers and therapist respectively. The qualitative data collected from therapist using an interview guide containing four items was coded in themes and analysed thematically as per the objectives. A five-point Likert-scale was used to measure the level of caregivers' involvement in early intervention process. The 6 items on caregivers' involvement were positively stated with the responses ranging from Never (0), Rarely (1), Sometimes (2), Very (3), and Always (4) as shown in the table below.

Table 4.4 Level of Caregivers' Involvement in Intervention Program

Response Rate	Never	Rarely	Sometime	Very	Always
Involvement factor	F (%)	F (%)	F (%)	F (%)	F (%)
1 How often are you involved in speech and language therapy services for your child?	0(0.0)	0(0.0)	0(0.0)	19(36.5)	33(63.5)
2 Do the therapist give you chance to talk about your problems?	0(0.0)	0(0.0)	0(0.0)	21(40.4)	31(59.6)
3 Does the therapist explain to you about the condition of the child before carrying out therapy?	0(0.0)	0(0.0)	1(1.9)	15(28.9)	36(69.2)
4 Are you given clear instructions by the therapist on how to follow the prescribed treatment program?	0(0.0)	0(0.0)	1(1.9)	36(69.2)	15(28.9)
5 Will you be willing to attend a one or two weeks training session for speech and language therapy (Circle one)?	0(0.0)	0(0.0)	0(0.0)	0(0.0)	52(100)
6 Do you Keep speech and language therapy appointments regularly?	0(0.0)	0(0.0)	3(5.8)	45(86.5)	4(7.7)
			TOTAL	52	100.0

It can be observed from the results in Table 4.4 that nearly two-third of the caregivers confirmed that they were always involved in speech and language therapy services for their children while a third of caregivers rated that they were very involved in therapy process. This implies that caregivers are

generally part and parcel of the therapy process and that their consistent engagement is integral part in early intervention process Caregiver's active involvement is considered vital for effective intervention (Granlund, Björck-Åkesson, Wilder & Ylven, 2008; Marshall & Goldbart, 2008; Sen & Goldbart, 2005). In order to attain a substantial caregiver involvement, the therapist is expected to engage them in decision making through mutual communication.

According to the findings in Table 4.4, slightly more than a half of the caregivers indicated that they were always involved by being given a chance to explain the problem of their children while nearly a half of caregivers confirmed that they very much allowed expressing themselves. It can also be observed that nearly two-third of the caregivers confirmed that the therapist always explained to them about the condition of the child before carrying therapy. Slightly more than a quarter of the caregivers also indicated that therapist was very committed to give explanations however, one reported that sometimes therapist did give an explanation though felt that the explanation received from the therapist was not sufficient.

Furthermore, caregivers were generally given clear instructions by the therapist on how to follow the prescribed treatment program as reported with more than a quarter indicating that they always understood the therapist and nearly two-third confirming that they were very much given clear instruction. The relationship between the doctor and the patient has been shown to be strongly associated with appointment adherence (Bultman & Svarstad, 2002). Good

caregivers-therapist relationship can contribute to improved appointment adherence and in turn effective involvement. The therapist-patient relationship seems to be an important factor for caregivers' involvement, which includes the process of inquiry for diagnosis, decision making, examination, prescription, and interaction.

All caregivers 52(100) confirmed that they were always willing to attend a one or two weeks training session for speech and language therapy to have capacity to help their children. Girolametto, Weitzman & Greenberg (2003) in their exploratory study about the outcome of in-service training of caregivers of a day care centres, engaged sixteen caregivers as experimental and control groups. The result supported the viability of training caregivers for effective early intervention. Ultimately, the caregivers should be equipped with knowledge and skills necessary to support the intervention process that helps to influence positive perception on early intervention efficacy.

The findings in Table 4.4 shows that, more than three quarters of caregivers were very committed in keeping speech and language therapy appointments regularly. However, a significant number of caregivers reported inconsistency to therapy appointment adherence though sometimes they did keep the therapy appointment.

The qualitative data was collected from the therapists using the interview guide containing four items. It was coded in themes and analysed thematically as per

the objectives. The first item in the interview guide sought to find out the levels of caregivers involvement: What levels do you think caregivers should be involved in an early intervention program for children with speech and language disorders? The participants expressed the importance of caregivers' involvement within an early intervention program that ought to be the requirement for any successful intervention. In terms of levels of involvement, the therapist reported that they involved caregivers in all levels, from assessment, intervention and follow-up process. Further, the therapist ensured clear therapist-client communication through phone call, text or home visit as well as supervised caregivers' therapy tasks.

Speech Therapist, "...from my perspective, I think the caregiver should be involved in the assessment, intervention and follow-up process. I therefore, must encourage caregivers to participate and empower them to be confident."

Caregivers are an integral component to the intervention process. They are just as important as the therapist since they are members of the intervention team because they are going to be implementing intervention therapy tasks at home mostly. Better yet, caregivers are necessary for intervention progress.

Table 4.5 Type of Caregivers' Involvement in Intervention Program

Type	Yes		No	
	Frequency	Percentage	Frequency	Percentage
Attend therapy appointments:	52	100.0	0	0.0
Attend meetings & conferences:	4	7.7	48	92.3
Communicate with staff in Decision making:	52	100.0	0	0.0
Workshops for Training and Education:	49	94.2	3	5.8
Parent-child therapy/activities:	52	100.0	0	0.0
Volunteer work:	2	3.8	50	96.2
One-on-one Intervention:	28	53.8	24	46.2
Counseling sessions:	49	94.2	3	5.8

One of the main levels of caregivers' involvement in early intervention process was to assess the types of involvement that caregivers engage in individually and therapist directed engagement. As depicted from table 4.5, all caregivers who responded, claimed that they attended therapy appointments, communicated with staff in decision making and got involved with parent-child

therapy. Majority of the caregivers attended workshops for training and counseling sessions whereas majority too did not attended meetings and conferences. Equally majority of the caregivers did not participate in volunteer work as type of involvement for effective early intervention for their children with speech and language disorders.

According to Kolt and McEvoy,(2007), caregivers involvement include; attending appointments to therapy, following advice on treatment, undertaking prescribed home programs, following the frequency of prescribed appointments as advised and caregivers' participation on treatment. The current study not only confirmed their findings but also found that counseling sessions and workshops for capacity building being crucial with all caregivers communicating with staff in decision making and taking part in Parent-child activities.

The second item in the interview guide sought to establish how therapist engaged caregivers in an early intervention program for children with speech and language disorders by assessing the types of involvement. The therapists reported that they involve caregivers in training (demonstrating), offering therapies at home, being close contact through communication and home visits, psycho social support, and decision making as a member of the rehabilitation team.

Speech therapist, "...i engage the caregivers by demonstrating treatment tasks and having them do those tasks in the clinic under supervision. I remain in

contact with the caregiver by phone, text or home visit to ensure that intervention tasks are being done.”

4.5 Barriers to Caregivers’ Involvement in Intervention Program

Objective three sought to find out the barriers to caregivers’ involvement in early intervention for children with speech and language disorders in Tenwek Hospital, Bomet County. Though caregiver involvement is integral and very important to the rehabilitation process, sometimes there are barriers to effective involvement. The respondents were provided with a list of possible barriers that they encountered to choose by ticking appropriately. Some of the presumed barriers included; financial constraints, Job and other job related commitments, time, Other children in the household, Lack of Family support, stress, Distance to the hospital, No speech therapist, no cure.

Table 4.6 Barriers to Caregivers' Involvement in Intervention Program

Response Rate	Never (0)	Rarely (1)	Sometime (2)	Very (3)	Always (4)
Barrier	F (%)	F (%)	F (%)	F (%)	F (%)
1. Other children in the household	1(1.9)	0(0.0)	0(0.0)	4(7.7)	47(90.4)
2. Job and other job related commitments	0(0.0)	0(0.0)	3(5.8)	9(17.3)	40(76.9)
3. Stress	0(0.0)	1(1.9)	4(7.7)	16(30.8)	31(59.6)
4. Financial Constraints	0(0.0)	0(0.0)	0(0.0)	5(9.6)	47(90.4)
5. Distance to the hospital	2(3.8)	6(11.5)	23(44.3)	17(32.7)	4(7.7)
6. Time	0(0.0)	0(0.0)	1(1.9)	12(23.1)	39(75.0)
7. No cure	2(3.8)	18(34.7)	29(55.8)	2(3.8)	1(1.9)
8. No speech therapist	0(0.0)	11(21.1)	33(63.5)	5(9.6)	3(5.8)
9. Lack of Family support	0(0.0)	0(0.0)	2(3.8)	10(19.3)	40(76.9)
Total	52	100.0			

As highlighted in Table 4.6, barriers to caregivers' involvement in their children's intervention program varied from individual to individual. Financial constraints and other children to care in the household were reported to be the most hindrance to caregivers' involvement. The result indicated that majorly caregivers were always barred from effective involvement for effective early intervention for their children with speech and language disorders by other

children in the household and financial constraints. Equally, of great concern as reported by three quarters of the caregivers, was job and other job related commitments, lack of family support and time. The high percentage witnessed in lack of family support may be attributed to cultural influence where females typically are the primary caregivers in a family in most African communities (Aspaas, 1998). This equally explains the high percentage of caregivers who brought or accompanied their children for rehabilitation being female as opposed to male.

Stress was reported as one of the major hindrance to caregivers' early intervention involvement. Despite a fact that majority of caregivers got involved in counselling sessions, the results from Table 4.6 revealed that more than a half of the caregivers were always distressed by the condition of their children. These findings are in line with Johnson and Hastings, (2002) findings that patients who are supported emotionally and helped by family members and clinicians are more likely to comply with the treatment procedures. Similarly, it confirms the findings of Benson, et al., (2008) that limited time and energy, socio-economic status, other children to care for, employment commitments, lack of support and stress has been cited to contribute to lack of caregivers' involvement.

Also, they were sometimes barred by distance covered to the hospital and lack of cure/medication. More than half of the respondents sometimes failed to attend clinic appointments due to their beliefs that there no cure to their children. This may have been contributed by lack of knowledge and

information about the disorder, treatment and the consequences of non-adherence resulting caregivers' relatively lower levels of involvement (Lazar et al., 1999).

This study confirms Ndung'u & Kinyua, (2007) survey on cultural perspective that determines the interpretations of language and speech disorders and their subsequent management in Kenya. They found that negative cultural beliefs attributing the disorder as a curse from God could result failure to seek treatment or too late. The result from Table 4.6 above confirms that as some caregivers who reported that there is no cure for their children's disorder may have attributed it as a curse from God. Beliefs that there is no cure results to inconsistent limited caregivers' involvement in early intervention program.

Lack of speech therapist was also reported to be a major concern to nearly two-thirds of the caregivers' involvement. Previous research found that sub-Saharan Africa lacks skilled professionals in speech-language pathology (Bangirana, et al., 2006). So this implies that many caregivers are not able to easily access speech and language therapy as well as involvement due to lack or unqualified speech and language professionals. Likewise, D'Antonio & Nagarajan, (2003) reported that there was increase in surgery for cleft palate in sub-Saharan Africa but access to speech and language therapy has not been the main challenge.

Qualitative data gathered from the third (3) item on the interview guide stated: What do you think might be the barriers to caregivers' effective involvement?

The respondent reported various barriers that may be fall on caregiver's involvement such as working status/other commitment, lack of confidence due to lack of knowledge(training) and clients overall condition. For example, a client with multiple medical needs at home who requires more care would be more difficult to encourage caregiver involvement than a client with minimal needs at home as reported by the therapist.

Therapist, "...working status; if a caregiver does not spend time with the client hence no intervention at home, lack of caregiver confidence in providing intervention independently and client's overall status may be a barrier to involvement."

Financial constraints, lack of family support, other sibling, have been mentioned in the previous studies (Benson, Karlof, & Superstein, 2008) but adding to the existing literature, the current study found lack of self-confidence and overall status of the client (multiple medical need) as a barrier.

4.6 Caregivers' Needs for Involvement in Intervention Program

Fourth objective sought to investigate the caregivers' needs and wants for effective involvement in early intervention program for children with speech and language disorder in Tenwek hospital. Both quantitative and qualitative data was collected. The researcher first sought to investigate the level of caregivers' satisfaction with the rehabilitation services for their children before assessing the needs and wants of caregivers for effective involvement. A five-

point Likert-scale ranging from Never (0), Rarely (1), Sometimes (2), Very (3), to Always (4) was used to measure the level of caregivers' satisfaction in early intervention process as shown in table below.

Table 4.7 Caregivers' Level of Satisfaction in Intervention Services

Category	Case	Frequency	Percentage
Are you satisfied with the rehabilitation of your child?	Never	0	0.0
	Rarely	1	1.9
	Sometimes	5	9.6
	Very	41	78.8
	Always	5	9.6
Total		52	100.0

The information from Table 4.7 above clearly portrays with little variations that more than three quarters of caregivers were very satisfied with the rehabilitation of their children in Tenwek Mission Hospital. Caregivers' satisfaction may have been determined by regular interaction with the therapist. This implied that there was good therapist-caregiver relationship that boosted positive attitude towards each other. Satisfaction of intervention process seems to be related to the quality, duration and frequency of interaction between the caregiver and therapist. The results in this study confirm the findings by Sharkawy, Newton & Hartley (2006) in Kenya who found that parents of

children with epilepsy who had unpleasant experiences with the clinician failed to keep appointments.

The findings of this study also are in line with the previous study which found that clinician’s attitude towards the patient and his ability to elicit and respect the patient's concerns as well as provide appropriate information and demonstration of empathy is of the utmost importance (Glogowska & Campbell, 2000).

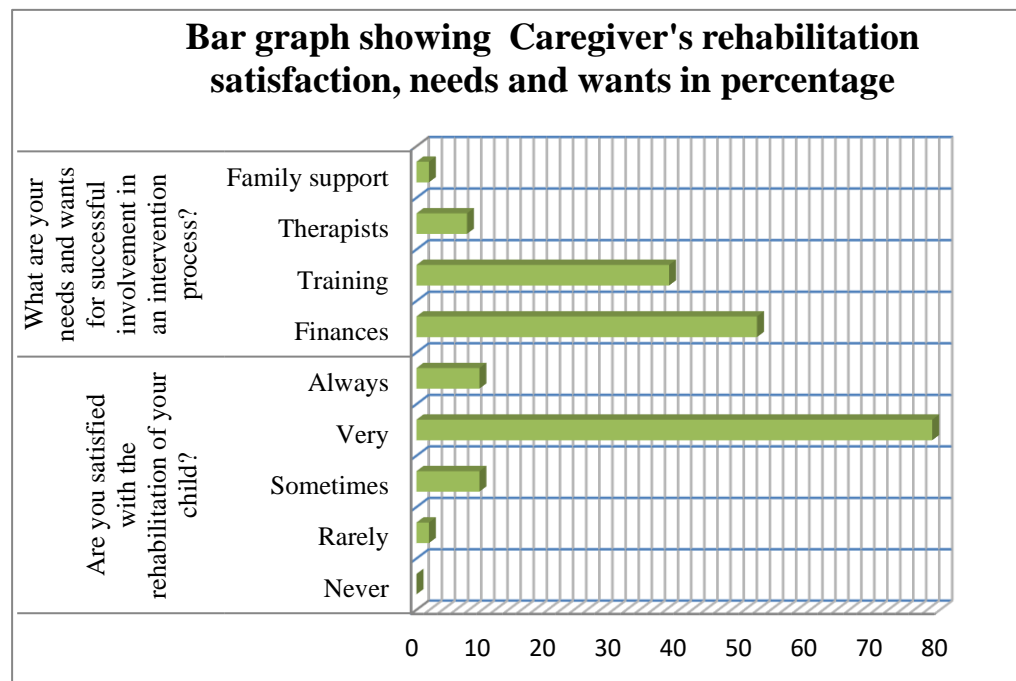


Figure 4.5 Caregivers’ Needs for Efficient Involvement

The results from Figure 4.5 above clearly shows that slightly more than half of the respondents settled that they needed financial empowerment and more than a third demanded more training. A significant portion of the respondent wanted more therapists availed in the hospital with minimal percentage registering need for family support in order to successfully get involved in the intervention

of their children. Financial assistance and capacity building through training were cited as the most crucial needs that caregivers were lacking though they served as prerequisite for effective involvement in an intervention program.

Cost is a fundamental expense incurred that has a far reaching effect on patient's compliance to intervention programs particularly for patients suffering from chronic conditions like speech and language disorders. The study findings are in line with the previous studies that found healthcare expenditure to be extremely unbearable portion of living expenses particularly for patients with chronic disease as the treatment period could be life-long (Ellis et al 2004). Therefore the cost and income becomes interrelated factors that determine the success of caregivers' involvement in an intervention program.

Ignorance about important issues, regarding the nature of the condition, the nature of the treatments and how successful it can be has been cited as one of the major obstacles to caregivers' involvement. The findings in Table 4.12 indicate the need for caregivers' capacity building if any substantial involvement in the intervention becomes the reality. Close to half of the caregivers, who responded to the questionnaire, reported that they needed to be equipped with knowledge and skills to help their children at home. The results from this study confirms the findings by Corlett, (1996) that Patient's knowledge about the condition is one of the primary reasons for medication non-adherence, failure to understand the importance of treatment. Caregivers

who are equipped with the knowledge about the condition as well as the management procedures enable them to make informed decisions concerning their health needs.

The fourth item in the interview guide also provided qualitative data concerning caregivers' wants and needs. The item sought to gather the opinion of therapists about the caregiver's wants and needs for effective involvement in early intervention process. The participants reported that the needs and wants depended on individuals and that it varied according to individual strengths and weaknesses. According to the therapist, each caregiver has inherent strengths and weaknesses and must be encouraged and empowered in those traits to utilise them in helping their children. They want substantial rapid improvement of the disorder though, some prefer not to be closely engaged possibly due to lack of family support hence feel overwhelmed or not confident due to lack of knowledge.

Speech Therapist, "...a caregiver often wants their loved one to be successful in the intervention process. On the contrary, a caregiver may not want to be as closely involved in the rehabilitation process and this should be considered in an intervention plan."

Roberts & Kaiser, (2011) in their analysis of 18 studies to establish the Effectiveness of Parent-Implemented Language Intervention found that,

parents successfully learned the strategies and used them when interacting with their child. Parents showed positive effect on their child's communication development and their effectiveness in helping their child as speech-language pathologists.

Previous studies have cited the integral role that parents (caregivers) play in an intervention process and the challenges involved. However, these studies have not comprehensively focused on the needs and wants of caregivers as they take a pivotal role in early intervention process. Marshall and Goldbart, (2008) exploration on the experience of parents of children with communication disorders using Augmentative Alternative Communication (AAC) found that parents are experts in their children's intervention process. Despite the vital role parents (caregivers) play in intervention process, previous studies have not focused on their wants and needs.

The current study found that caregivers needed financial empowerment, more training, access to therapists and family support in order to successfully get involved in the intervention of their children with speech and language disorders. In respect to these findings, the current study therefore fill gap that has been neglected for decades by assessing the primary needs of caregivers for effect involvement. Furthermore, it offers a solution to Bennett's suggestion that further research was needed to investigate parents' needs in order to best accommodate each family (Bennett, 2012).

CHAPTER FIVE:

CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter presents the summary of the findings, conclusions and recommendations from the study findings, and finally the suggestions for further research. The study investigated caregivers' involvement in intervention for children with speech and language disorders in Tenwek Hospital Bomet County, Kenya. The study was guided by the following objectives: objectives of the study were to: Investigate caregivers' awareness of speech and language disorders intervention process in Tenwek Hospital; Establish caregivers' involvement in intervention programs for children with speech and language disorders; Find out the barriers to caregivers' involvement in intervention programs for children with speech and language disorders, and Investigate caregivers' needs for involvement in intervention programs for children with speech and language disorders in Tenwek Hospital.

The problem statement centred on caregivers' involvement in intervention program for children with speech and language disorders. The study assumed that the involvement of caregivers would positively impact on the efficiency of intervention programs that are inclusive. In respect to this goal, this presents recommendations made on what the stakeholders can do in regard to caregivers' involvement in intervention programs.

5.2 Summary of the Research Findings

The purpose of the study was to objectively seek information on the caregivers' involvement in intervention programs for their children with speech and language disorders. The questionnaires that were properly filled and collected were adequate to viable analysis.

The first objective was to investigate caregivers' awareness of speech and language disorders intervention process in Tenwek Hospital, Bomet County. The results under this objective include: Majority of the caregivers were aware of the disorders of their children. Many of the caregivers reported that their children had more than one disorders however, communication disorder was common. Despite these caregivers' awareness of their children's disorder, majority were not conversant with the cause of the disorder.

The second objective was to establish caregivers' involvement in intervention programs for children with speech and language disorders in Tenwek Hospital, Bomet County. The caregivers rated themselves highly on the level of involvement that they always got involved in speech and language therapy services for their children .Most of the caregivers confirmed that the therapist always gave them chance to talk about their problems of their children and that the therapist in most occasions explained to them about the condition of the child before carrying out therapy though. Furthermore, caregivers reported that though they were given instructions by the therapist on how to follow the prescribed treatment program they were not always clear. All caregivers who

participated in the study were always willing to attend a one or two weeks training session for speech and language therapy.

Majority of the caregivers claimed to be very committed to attend therapy appointment regularly and they always kept speech and language therapy appointments regularly though some agreed that sometime they did not keep the appointment. In assessing the types of caregivers' involvement, it was depicted that all caregivers got involved by attending therapy appointments, communicating with staff in decision making and also get parent-child therapy. Equally, substantial number of caregivers confirmed attending workshops for training and counseling sessions.

Of great concern is that most caregivers neither attended meetings and conference nor participate in volunteer work as type of involvement for effective early intervention for their children with speech and language disorders. Similarly, the therapist reported that they involved caregivers in all levels, from assessment, intervention and follow-up process. These involved trainings (demonstrating), offering therapies at home, close contact through communication, and home visits, psycho social support, and decision making as a members of the rehabilitation team.

The third objective of this study sought to find out the barriers to caregivers' involvement in intervention process for children with speech and language disorders in Tenwek Hospital. The findings showed that most caregivers were always barred from effective involvement for effective early intervention for their children majorly by other children in the household, financial constraints and job and other job related commitments. Lack of family support, limited

time and stress were also cited as significant hindrances to caregivers' effective involvement. Also, some respondents claimed that they were sometimes barred by distance covered to the hospital though this factor interrelates to financial constraints. Significant number of caregivers believed that cure to the disorder was not guaranteed hence little efforts to effective involvement. Equally, some cited lack of enough speech therapist and consistence as a hindrance to their involvement.

The therapists also reported various barriers that may be fall on caregiver's involvement such as working status/other commitment, lack of confidence due to lack of knowledge(training) and clients overall condition. Financial constraints, lack of family support, other sibling, were also mentioned by the therapists as main barriers to caregivers' involvement in early intervention for children with speech and language disorders in Tenwek Hospital Bomet County, Kenya.

The fourth objective sought to investigate caregivers' needs for involvement in intervention program for children with speech and language disorders in Tenwek Hospital. In assessing the needs and wants of caregivers, the research sought to understand caregivers' level of satisfaction with the intervention process. Though with little variations, caregivers generally confirmed that they were satisfied with the rehabilitation process of their children in Tenwek Mission Hospital. However, they cited a substantial number of needs and wants that could improve their involvement in the intervention process.

Slightly more than half of the respondents settled that they needed financial empowerment to be able to manage the costs involved in the intervention process. Capacity building was equally rated vital as a considerable number of caregivers demanded for more training. A significant number of caregivers wanted more therapists available in the hospital for easy access to speech and language therapy services. Family support be it physical support, financial or psychosocial was also cited as a significant requirement for a successful involvement of caregivers in the intervention of their children with speech and language disorders.

Furthermore, the therapists reported that the needs depended on individuals and that it varied according to individual strengths and weakness. For instance; a caregiver often wants their loved one to be successful in the intervention process. On the contrary, a caregiver may not want to be as closely involved in the rehabilitation process due to psychosocial issues, stress, and lack of knowledge or the client's overall condition.

5.3 Conclusion

The study resulted in four conclusions as follows. Firstly, it was evident from the findings that slightly more than a half of the caregivers were aware of their children's disorder although a significant percentage of this population was not conversant of the cause. Secondly, caregivers always got involved in speech and language therapy, communicated well with the therapists about their problems and got child condition explanation from the therapists. The therapist gave instructions on how to follow prescribed treatment program though not clearly conceived by some caregivers. Caregivers were always ready to attend training for speech and language therapy and kept such therapy appointments though with underlined challenges. Though with little variations, the caregivers expressed their satisfaction with the rehabilitation of their children in Tenwek Mission Hospital. .

Thirdly, caregivers were always barred in their level of involvement by attention of other children in the household, job and other job related commitments with financial constraints being the core barrier. Lack of family support, time and stress equally had far reaching effects on caregiver involvement. Equally, caregivers lack confidence to carry out some therapeutic activities and the overall status of the condition of their children discouraged them from effective involvement. Also, they were sometimes barred by distance covered to the hospital, beliefs about lack of cure and lack of enough speech therapist in the hospital. Lastly, caregivers needed financial

empowerment to a large extent, capacity building through training, frequent access to therapists in the hospital and at least some level of family support in order to successfully get involved in the intervention of their children with speech and language disorders.

5.4 Recommendations

By investigating the effects of caregivers' awareness of speech and language disorders on early intervention program in Tenwek Hospital, there is need to emphasize on caregivers' capacity-building, knowledge enhancement and self-confidence for effective early intervention. Establishing the extent of caregivers' involvement in early intervention for children with speech and language disorders in Tenwek, highlights the vital role caregivers play as rehabilitation team members and procedural involvement for effective intervention. Findings from the barriers to caregivers' involvement in intervention for children with speech and language disorders, provides a platform to put in place measures for alleviation of involvement barriers so as to enhances effective intervention for remarkable client improvement.

The effort to investigate caregivers' needs for involvement in intervention program for children with speech and language disorders in Tenwek Hospital enhances good practices values. It gives an insight that clinician should consider caregivers wants and needs when determining an intervention plan for the client. Each caregiver has inherent strengths and weaknesses and must be encouraged and empowered in those traits.

Based on the findings of the study, the researcher recommends:

- i. The need for more public sensitization on the cause, signs, prevention mechanisms and best therapy treatment programs available for children with speech and language disorders.

- ii. The hospital to employ more speech and language therapist for more engagement with speech and language patients and their caregivers for better involvement.
- iii. There is also need to involve all stakeholders in the ministry of Health and Education to subsidize medication and financial bill associated with children speech and language disorders.
- iv. The evidence adds strength to recommendations that caregiver empowerment in terms of knowledge, resources and consideration of the wants and needs in their participation need to become integral components of early intervention services for young children with special needs.

5.4.1 Suggestions for Further Studies

Further studies should focus on the caregivers' willingness to be involved in a rehabilitation process. Despite therapists' effort to effectively engage the caregivers, they may not want to be as closely involved in the rehabilitation process. Further studies should also find out whether the severity of the client's condition (multiple medical needs) and overall status may be a barrier to effective caregiver involvement.

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APPENDICES

Appendix A: Questionnaire for the Caregiver (parent/guardian)

This questionnaire is intended to seek information on the level of *caregivers' involvement for effective early intervention for their children with speech and language disorders*. Please feel free and answer all the questions accurately. *Note that the response you give here will NOT be used against you.*

Demographic Data

Gender of Caregiver: Male Female

Residence: Rural Urban

Date of Birth of the child: ____/____/____ other sibling _____

1. Who accompanies the child for treatment?

Mother Father Guardian

2. What is your highest level of education? Please tick in the right box

1. University 2. Tertiary 3. O' level

4. Primary 5. None

3. What is your current employment status? Please tick in the right box

1. Salaried 2. Self-employed 3. Housewife

4. Retired 5. Student

MAIN QUESTIONS

A). Caregivers Awareness of the Disorder

1. What do you think is the problem of your child?

2. What do you think caused the disorder to your child?

B). Level of Involvement:

Use a scale of 0-4 where 0=Never, 1=Rarely, 2=Sometimes, 3=Very and 4=Always (Tick)

	Questions	0	1	2	3	4
1	How often are you involved in speech and language therapy services for your child?					
2	Do the therapist give you chance to talk about your problems?					
3	Does the therapist explain to you about the condition of the child before carrying out therapy?					
4	Are you given clear instructions by the therapist on how to follow the prescribed treatment program?					
5	Will you be willing to attend a one or two week training session for speech and language therapy (circle one)?					
6	Do you keep speech and language therapy appointments regularly?					

7. How are you involved in speech-language therapy program for your child?

Type of Involvement	Attend therapy appointments	Attend Meetings & Conferences	Communicate with staff (Decision making)	Training & Education/ workshops	Parent-Child Activities/ Therapy	Volunteer Work	One-on One Instruction	Counseling sessions
Tick								

C). Barriers to Efficient Caregivers Involvement

If you rarely keep your appointments, what could be the reasons that make you not to attend clinic regularly?

Use a scale of 0-4 where 0=Never, 1=Rarely, 2=Sometimes, 3=Very and 4=Always (Tick)

Barriers	0	1	2	3	4
Other children in the household					
Job/other commitment					
Stress					
Finances					
Distance					
Time					
No cure					
No speech therapist					
Lack of family support					

D). Caregivers Needs for Involvement

1. Are you satisfied with the rehabilitation process of your child?

Never [], Rarely [], Sometimes [], Very [], Always [],

2. What are your needs and wants for successful involvement in an intervention process?

.....

Appendix B: Interview Guide for the Therapists (SLP/OT)

This interview guide is intended to seek information on the level of caregivers' involvement for effective early intervention for their children with speech and language disorders. Please feel free and answer all the questions accurately. Note that the response you give here will NOT be used against you.

General Information: Date _____ Time _____

Gender: Female [] Male []

Education Level: Diploma [] Graduate [] Post-graduate []

Period of service: Below 1 [], 1-5 [], Above 5 []

1. What levels do you think caregivers should be involved?

.....
.....
.....

2. How do you engage the caregivers in the intervention process?

.....
.....
.....

3. What do you think might be the barriers to caregivers' involvement?

.....
.....
.....

4. What do you think are the caregiver's needs for successful involvement in an intervention process?

.....
.....
.....

Appendix C: Tenwek Map



Tenwek Hospital Map

Appendix D: Approval Letters



TENWEK HOSPITAL
A Ministry of Africa Gospel Church

Postal Address:
P.O Box 39
Bomet-Kenya

Telephone: (254) 728-091900, 20-2045542
E-mail: tenwek@tenwek.com
Website: www.tenwekhospital.org

15th February, 2017

Mr. Obure Sianyoo
Kenyatta University
P.O. Box 43844,
Nairobi.

Dear Mr. Obure,

Re: IREC Approval of Research Study

Thank you for your application to have us review your research proposal entitled
"Caregivers involvement for effective early intervention for children with speech and
language disorders in Tenwek Hospital, Bomet County."

We are pleased to inform you that Tenwek Hospital Institutional Research and Ethics
Committee reviewed and approved your proposal at its meeting on 1st February, 2017.

If appropriate, we would appreciate follow-up on the results of your study.

Blessings on your research!

Sincerely,

Stephen L. Burgert, MD

Medical Superintendent

Chair, Tenwek Hospital Institutional Research and Ethics Committee.

**MEDICAL SUPERINTENDENT
TENWEK HOSPITAL
P. O. Box 39
BOMET - 20400**

COUNTY GOVERNMENT OF VIHIGA

E-mail: vihigahospital@gmail.com
Mobile No: +254-796 057 881,
Ambulance + 254-722915987



OFFICE OF THE MEDICAL
SUPERINTENDENT
VIHIGA COUNTY REFERRAL HOSPITAL
P.O. BOX 1069 - 50300
MARAGOLI
Date: 7TH FEBRUARY, 2017.

DEPARTMENT OF HEALTH

TO WHOM IT MAY CONCERN

RE: SIANYO E. OBURE: E55/27869/2014

The above named speech therapy student was approved to do his research/pilot study in our facility in October 2016.

The study was about "*Care Givers Involvement for Effective Intervention For Children With Speech Language Disorders.*"

He was attached to occupational therapy department for one week. He particularly paid attention to cerebral palsy children who develop speech slowly and late in life. Other children included the autistic children, down syndrome children etc.

Abisai H. Moyi
Occupational Therapist In Charge
For Medical Superintendent

VIHIGA COUNTY REFERRAL HOSPITAL.



KENYATTA UNIVERSITY
ETHICS REVIEW COMMITTEE

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

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

Our Ref: KU/R/COMM/51/844

Date: 15th November, 2016

Siano Elick Obure
Kenyatta University
P.O. Box 43844 – 00100
NAIROBI

Dear Siano,

APPLICATION NUMBER **PKU/599/1684** – “CAREGIVERS’ INVOLVEMENT FOR EFFECTIVE EARLY PREVENTION FOR CHILDREN WITH SPEECH AND LANGUAGE DISORDERS IN TENWEK HOSPITAL, BOMET COUNTY, KENYA”

1. IDENTIFICATION OF PROTOCOL

The application before the committee is with a research topic “Caregivers’ Involvement for Effective Early Prevention for Children with Speech and Language Disorders in Tenwek Hospital, Bomet County, Kenya” received on 25th October, 2016 and discussed on 8th November, 2016.

2. APPLICANT

Siano Elick Obure

3. SITE

Bomet County, 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 15th November, 2016.

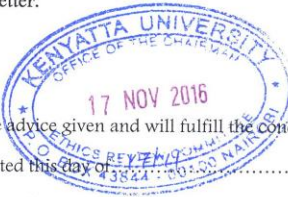
5. ADVICE/CONDITIONS

- 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 board 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.

DR. TITUS KAHIGA
CHAIRMAN ETHICS REVIEW COMMITTEE



I, SIANO ELICK OBURE accept the advice given and will fulfill the conditions therein.

Signature..... TEO Dated this day of 2016.

cc. Vice-Chancellor
DVC-Research Innovation and Outreach