

Caregivers' Needs for Involvement in Early Intervention for Children with Speech and Language Disorders in Tenwek Hospital, Bomet County, Kenya

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Abstract: The purpose of this study was to investigate caregivers' wants and needs for involvement in early intervention program for children with speech and language disorders in Tenwek Hospital. The effort to consider caregivers wants and needs enhances good practices values. It gives an insight that caregivers' wants and needs are integral components in determining an early intervention plan for the children with speech and language disorders. The study was guided by Normalization Process Theory by May, (2006).

Method and Materials: The study adopted a case study research design and 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. 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.

Results: The study found that 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.

Conclusion: It is evident that each caregiver has inherent strengths and weaknesses and must be encouraged and empowered in those traits for better participation at all levels. The study recommends that clinicians should consider caregivers wants and needs when determining an intervention plan for the children with speech and language disorders. There is also need to involve all stakeholders in the ministry of health to subsidize medication and financial bill associated with children speech and language disorders.

Keywords: caregivers, needs, involvement, early intervention, speech and language disorders, Kenya.

1. INTRODUCTION

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, 2003).

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 (Brodsky, Thomson, Thompson & Fine, 2005). An educated caregiver may serve a vital 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' wants and needs for involvement in early intervention program for children with speech and language disorders in Tenwek Hospital, Bomet County.

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).

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' wants and needs for effective involvement in early intervention programs for children with speech and language disorders and the barriers to effective engagement.

In Kenya, Children with speech and language disorders in rural areas have not been well attended. Following the need, speech and language pathology rehabilitation has been initiated through an outpatient clinic in Tenwek Mission Hospital and a mobile clinic in Bomet County. 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 whether the therapists take into consideration the wants and needs of the caregivers in early intervention process for their children their children with speech and language disorders. Therefore; this study sought to investigate caregivers' wants and needs for effective involvement in early intervention program for children with speech and language disorders in Tenwek Hospital, Bomet County.

The findings of this study is likely to give an insight on the significance of considering caregivers wants and needs for effective involvement in planning and implementation of early intervention programs on speech and language therapy. It also adds knowledge on the importance of prioritising caregivers' wants and needs and their relevance in early intervention services for the children with speech and language disorders in Bomet County, Kenya and Sub-Saharan African countries at large. It further assists caregivers on building knowledge about speech and language pathology and creates a positive attitude toward early interventions. It further adds to knowledge and provides literature to the government, non-governmental organization, the university and other scholars on caregivers' vital role of making decision for paediatric speech and language intervention.

Limitations of the Study:

The study targeted caregivers of children with speech and language disorders whose children are rehabilitated in Tenwek Mission Hospital only in Bomet County. Since wants and needs depend on individuals, social and economic factors, the application and generalisation of the study findings to other caregivers in other counties should be done with caution.

2. MATERIALS AND METHOD

The study adopted a case study design which employs both quantitative and qualitative approaches. . 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 utilized all the accessible population. Sixty (60) caregivers and two therapists formed the study population. Data was collected by administering questionnaires to the caregivers and interview guides to therapists. The questionnaire contained closed-ended items on a five-point Likert-type scale of; Never, Rarely, Sometimes, Very, Always. Never coded as "0" imply not satisfied at all hence ineffective early intervention while always coded as "4" implying highly satisfied hence very effective early intervention. Caregivers were also listed their wants and needs which were coded and analysed quantitatively. The questions on the interview guide with a set of probable responses were supplied and the responses from the therapists recorded appropriately. 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 analyzed thematically.

3. RESULTS AND DISCUSION

Caregivers' Needs and Wants for Effective Involvement:

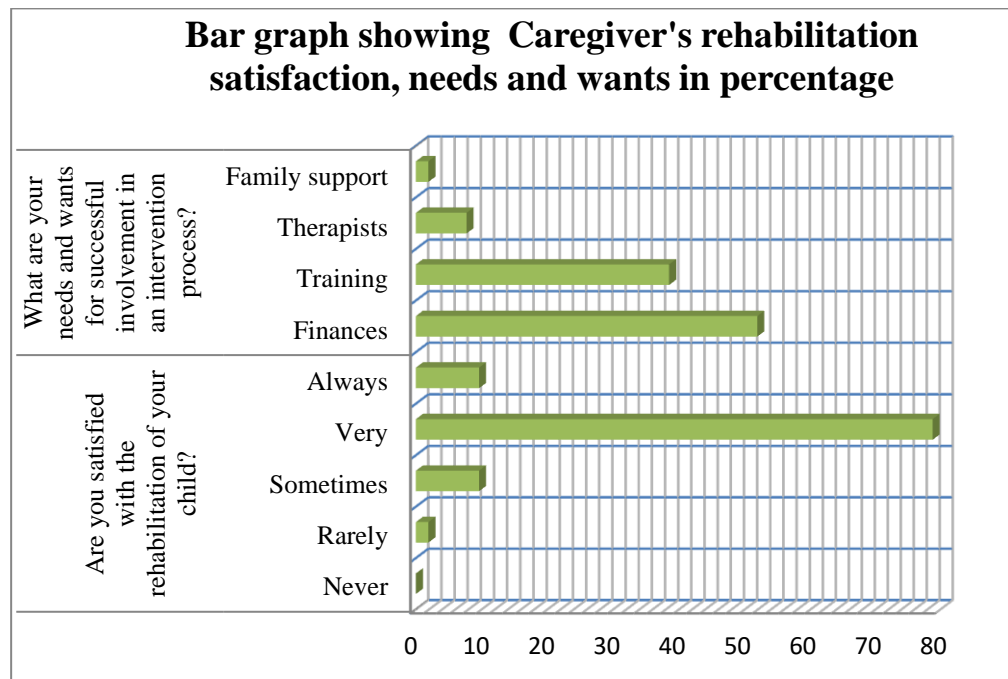
The study investigated caregivers' needs and wants for effective involvement in early intervention program for children with speech and language disorder in Tenwek hospital. Both quantitative and qualitative data was collected. The researcher first sought to investigate the level of caregivers' satisfaction 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 1: Caregivers' Level of Satisfaction in Early 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 1 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).



Source: Field data, 2017

Figure 1: Caregivers' Needs and Wants for Effective Involvement

The results from Figure 1 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 available 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 serve as prerequisites 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 an 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 become 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 figure 1 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 confirm 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 weakness. 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 and wants of caregivers for effect involvement. Furthermore, it offers a solution to Bennett's suggestion that further research was needed to investigate parents' wants and needs in order to best accommodate each family (Bennett, 2012).

4. SUMMARY, CONCLUSION AND RECOMMENDATIONS

The objective of the study centred on caregivers' wants and needs for involvement in early intervention program for children with speech and language disorders in Tenwek Hospital. The study assumed that considering caregivers' wants and needs in early intervention program would positively impact on the effectiveness of intervention that is more inclusive. In respect to this goal, the study sought to investigate caregivers' wants and needs for involvement in early intervention program for children with speech and language disorders in Tenwek Hospital. In assessing the needs and wants o 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 availed 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 and wants 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 psycho social issues, stress, and lack of knowledge or the client's overall condition.

Conclusion:

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.

Recommendations:

The effort to investigate caregivers' wants and needs for involvement in early 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. The evidence adds strength to the 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.

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