ISSN 2348-3156 (Print)
International Journal of Social Science and Humanities Research ISSN 2348-3164 (online)
Vol. 6, Issue 2, pp: (13-21), Month: April - June 2018, Available at: www.researchpublish.com

Caregivers' Extent of Involvement in Early Intervention Program 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 establish the extent of caregivers' involvement on early intervention of children with speech and language disorders in Tenwek Hospital, Bomet County. The involvement of caregivers and families of children with communication disorders is vital for any effective early intervention services. The study was guided by Normalization Process Theory by May, (2006).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 utilized 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. The study found that Caregivers were involved in the intervention mainly by attending therapy appointments, communicating with staff in decision making and parent-child therapy. In conclusion, caregiver empowerment and participation at all levels need to become an integral component of early intervention services for young children with speech and language disorders. The study recommends need for more speech therapist, public sensitization on the cause, signs, prevention mechanisms and accessible treatment programs for children with speech and language disorders. It is hoped that the study findings will 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 disorders in Kenya.**

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

1. INTRODUCTION

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, 2003).

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.

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.

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 found out the effects of caregivers ignorance 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 (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 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. Following the need for speech and language pathology rehabilitation, an outpatient clinic in Tenwek Mission Hospital and a mobile clinic at Bomet Primary School have availed therapy services and engaged 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, the current research sought to establish the extent of caregivers' involvement for effective early intervention for children with speech and language disorders in Tenwek Mission Hospital, Bomet County Kenya.

Caregivers' Extent of Involvement in Early Intervention program for Children with Speech and Language Disorders:

Early intervention services are crucial for caregivers and familiar context of children with speech-language disorders. 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). 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).

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.

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.

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). 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 therapy process in Tenwek hospital, 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 is realised to the child's communication skills is achieved when parent acquire information and adopt new ways of communicating with their children.

Caregiver empowerment is an integral component early 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

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 communicate 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. 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 Tenwek hospital Bomet County.

The research findings of this study 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, 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 in 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. Therefore, 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

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International Journal of Social Science and Humanities Research ISSN 2348-3164 (online)
Vol. 6, Issue 2, pp: (13-21), Month: April - June 2018, Available at: www.researchpublish.com

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 no involvement at all hence ineffective early intervention while Always coded as "4" implying highest level of involvement hence very effective early intervention. The interview guide was used in discussions with therapists to help the researcher to obtain first-hand information. 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

Level of Caregivers' Involvement for Effective Early Intervention:

The study sought to establish the the extent of caregivers' involvement in early 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 objective. 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 1: Level of Caregivers' Involvement for Effective Early Intervention (N=52)

	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 1 above 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 1 above, 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 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 1 above shows that more than three quarters of caregivers was very committed in keeping speech and language therapy appointments regularly. However, a significant number of caregivers reported inconsistence 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.

Types of caregiver's Involvement in Early Intervention Programs:

Table 2: Type of Caregivers' Involvement for Effective Early Intervention

	Yes		No	
Type	**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. It is clearly depicted from table 2 above that all caregivers attended therapy appointments, communicated with staff in decision making and get 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 a 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.

Further, items 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. SUMMARY, CONCLUSION AND RECOMMENDATIONS

The problem statement centred on caregivers' involvement for effective early intervention program for children with speech and language disorders. The study assumed that the involvement of caregivers would positively impact on the effectiveness of early intervention programs that are inclusive

Summary of the Research Findings:

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

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.

Conclusion:

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. .

Recommendations:

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. The hospital and government should ensure accessibility of more speech and language therapist for effective engagement with speech and language patients and their caregivers.

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