Medical Journal of Zambia, Vol. 42, No. 4: 164-169 (2015)

ORIGINAL ARTICLE

Mothers' Perceptions on the Needs of Adolescent Children with Intellectual Disabilities at George Clinic, Lusaka, Zambia

JK Nkhosi, JA Menon

University of Zambia, Lusaka

ABSTRACT

Study objective: This study explored mothers' perceptions of the social and emotional needs of their adolescent children with intellectual disability (ID) at George clinic in Lusaka.

Design: The qualitative method was utilized to conduct the study with the use of focus group discussions and home observations.

MAIN OUTCOMES

Sample: Nineteen mothers of adolescents with ID who no longer attend physiotherapy sessions at George clinic were purposefully selected for the study.

Measures: A structured interview guide was used to collect data from two focus group discussions while a Home Environment Potential Assessment (HEPA) guide was used to conduct a series of six observations on two homes.

Procedures: Participants were recruited during home visits after being introduced to the researcher by the field staff of Archie Hinchcliffe Disability International (AHDI). Participants were parents whose ID adolescent children had used physiotherapy in early childhood, but had stopped due to mobility problems.

Data Analysis: Interviews were transcribed and translated and meanings derived from the common themes which were synthesized into the final report.

Results: Mothers reported that adolescents with ID have social needs and emotional feelings like other people. However they face challenges when it comes to having their social needs met which leads to emotional difficulties. Inability to contribute to play and other interactions meaningfully leads to social isolation by peers. Mothers respond to these needs by putting in place ways in which the child can still continue to interact with peers, and other members of society. During the transition into adolescence and young adulthood, support from the public sector, such as special education, prompt primary health care provision and social services, is inadequate.

Conclusions: Despite the numerous challenges involved in raising their adolescent children, mothers still were able to articulate how they supported the child socially, and in so doing met his or her emotional needs as well. There is therefore need to formulate policies on adolescent transitional services.

INTRODUCTION

Adolescents with intellectual disabilities (ID) are prone to experience more social and emotional difficulties in comparison to their non-

---

Corresponding author:
JK Nkhosi
C/o J. Nkhosi Technical Consultants,
P.O. Box 320369, Lusaka.
Email: skumalinga@gmail.com

Key words: *Intellectual disability, perceptions, adolescents, social and emotional needs.*

intellectually-disabled counterparts [1]. This is likely to occur because they are vulnerable to social exclusion and other challenges that relate to limitations in adaptive functioning [1]. It is common for these needs to go unrecognized and unmet by professionals despite the fact that the mother makes a significant contribution to the child's well-being [2].

This study explored the social and emotional needs of adolescents with intellectual disability (ID) as perceived by their mothers. Presence of social and emotional needs are easily noticed by mothers because they are with their children almost all the time and can define what is best for him or her. Thus they are able to speak out on behalf of their children [3].

The findings of this study will guide the practice of various professionals that come into frequent contact with mothers of children with (ID) on how best to offer psychological and other forms of support to both.

Furthermore, the findings of this study will provide information to policy makers in the Ministries of Health, Education, and Community Development and Mother and Child Health to enable them put in place measures to follow up adolescents no longer benefitting from interventions.

METHODS

The phenomenological design was used to explore mothers' perceptions of the social and emotional needs of adolescent children with intellectual disability (ID) from two focus group discussions.

The ethnographic qualitative design was used to observe mothers and relevant others in their environment through a series of six observations on two homes.

RESEARCH INSTRUMENTS

The Focus Group Discussion Guide

A structured interview guide which the researcher compiled using study research questions was used to direct the focus group discussions, along with probing questions where appropriate.

The Home Environment Potential Assessment (HEPA) Observation Tool

The researcher used a checklist adapted from items on the Home Environment Potential Assessment (HEPA) schedule to observe the social and emotional interaction between the mothers and their adolescent children with ID in their homes [4].

DATA COLLECTION PROCEDURES

Sample

The target population consisted of mothers that give care to and spend most of the time with their adolescent children with ID in Lusaka's high density area of George compound, who no longer bring them for physiotherapy services to George clinic. The sample consisted of seventeen mothers who participated in the focus group discussions and two mothers selected for observations with their adolescent child at home.

Sampling and Recruitment Procedures

The purposive sampling procedure was used to recruit participants for the study. The participants were identified with the help of the Archie Hinchcliffe Disability Intervention (AHDI) field staff who conduct physiotherapy services at George clinic and the University Teaching Hospital.

Data analysis

Focus group and home observations qualitative data were analyzed using Colaizzi's (1978) method of observing and analyzing human behavior within its environment to examine nonverbal behaviors and Giorgi's (1970) method of reading the entire written description in order to get a sense of the whole, cited by [5].

Limitations of the study

Medical records or case notes that indicate a diagnosis of intellectual disability were not used to shortlist participants for the study as they were not available. Furthermore, findings of the study cannot be generalized because it dealt with a particular group of respondents.

Credibility of study

The Nyanja focus group discussion guide was tested for reliability and accuracy on a similar sample of four mothers in Chawama compound which is also a high density area. Study variables such as the words "emotion", "social", "needs" and "intellectual disability" were discussed with the mothers, field staff and the translators to ensure that they represented the objectives of the study. In addition, a Nyanja-English dictionary was used to verify the meaning of these words and ensure they were appropriately used in the study [6]. No major changes were made to the questionnaire except to simplify some of the Nyanja words into the Nyanja commonly spoken in Lusaka's compounds, known as *"town Nyanja"*.

RESULTS

Findings from the data collected, have been described according to the study objectives.

Mothers' Perceptions of the Social Needs of their Adolescent Child

Adolescents with intellectual disability like to play with their peers and interact with people who are friendly to them. However, it is not always easy for them to be accepted by other people because of their limitations in various dimensions of their lives.

Mothers' Response to the Social Needs of their Adolescent Child

Mothers set limits and define boundaries on individuals who mistreat their child and respond to social needs by involving the adolescent in activities of daily living.

Mothers' Perceptions of the Emotional Needs of their Adolescent Child

Children show happiness by excitement, laughing and smiling, when basic physiological as well as social needs are met. However, when their needs are not met they are hurt and express this by crying, anger, sadness and self-isolation.

Mothers' Response to the Emotional Needs of their Adolescent Child

When most mothers notice that their child is unhappy they do not leave the child alone, but instead they stay with him/her to counsel, encourage and comfort him/her.

Mothers' Perceived Support from Professionals and other sources

Most mothers are supported by their other children, husband or nuclear family. They are also encouraged through faith in God. The extended family supports mothers and in the case where help is not available friends, neighbours and church mates assist materially and socially. All mothers pointed out that support from the Non-Governmental Organizations and government professionals was not forthcoming.

DISCUSSION

Children and adolescents with ID are so close to their mothers that they express their distress at being left by crying continuously. They show symptoms of somatization during the period of absence. This finding is similar to a study by [7] which discovered that children with intellectual disabilities are at significant risk of psychopathology due to their increased rate of exposure to psychosocial disadvantage. Furthermore, Bronfenbrenner's Ecological Systems Theory posits that the emotional and social development of a child or adolescent takes place within the context of a social environment, in this case the family or microsystem [8]. Emotional and social development occurs due to proximal processes between the adolescent and his or her mother, father, siblings or other family members.

Children and adolescents with ID enjoy interacting with different kinds of people such as siblings, neighbours, peers, fellow church members and relatives. They like to play with friends around the home environment which is an example of the mesosystem, made up of extended family members, peers and neighbours that surround the home environment [8].

Since adolescents with intellectual disability (ID) enjoy interacting with their peers, mothers deliberately provide an environment within their homes within which they can play and interact with other children. This is contrary to [9]'s assertion that parents may not be able to provide an environment where social development of the child with ID takes place.

Adolescents show contentment and happiness when their basic and social needs are met. At the other end of the scale adolescents with ID become very unhappy when both biological and social needs are not met. Sometimes they show this unhappiness in a justifiable manner while at other times they inappropriately isolate themselves, cry incessantly and exhibit unreasonable anger expressed as a behavioural disturbance.

This finding is confirmed by previous similar research findings of a high prevalence of emotional and behavioural difficulties amongst children with intellectual disability by [3]. Besides, research by [10] of a population-representative sample, found that ID is an independent predictor of conduct problems and emotional symptoms in adolescents.

Most mothers are able to determine causes of unhappiness in their children. They mentally carry out a check as to what they have done or not done which could be causing the unhappiness. Once they have noted the reason for the unhappiness they respond in a supportive way to their child. If they do not do so the child can become ill. They try to placate the child by carrying him or her on their back and walking around. Many of the children like the physical closeness this brings and stop crying. Carrying a child on the back is a common traditional way of baby sitting or child minding and is common in the Zambian and African society. Furthermore, mothers counsel, encourage, reassure and comfort their child. Such parenting practices in which there is body contact are supported by an alternative parenting style that has been described in the literature - the proximal parenting style described by [11]. The proximal parenting style conveys empathy, love and care to an adolescent child with ID who is in emotional distress [11]. Parenting styles are used to regulate emotions of children when undergoing stress, according to the Tripartite Model of the Impact of the Family on Children's Emotion Regulation and Adjustment [12].

Furthermore, Floyd, Harter & Costigan 2004, cited by [13] states that parents have specific practices in parenting children with intellectual disabilities and may employ a number of positive parenting strategies.

Professionals in the curative part of the primary health care clinic in George compound do not comprehend the difficulties that children with intellectual disabilities encounter; as well as the emotional distress that occurs to mothers when they are not attended to with patience, care and understanding in the outpatient department.

This finding is similar to research conducted by [14] in which mothers pointed out that doctors and nurses lacked understanding of their child's condition resulting into caregiver role strain. This finding is also similar to that of [15] in which mothers were willing to challenge professionals' views with regard to their sons and daughters and advocate for their child as mothers. Adolescents with ID are unable to access help from formal organizations unlike in the early childhood period of their lives. This finding is similar to research conducted by Parish et al, (2006) cited by [13] which accounts that support services rapidly declined when the child reached adolescence, because they were expected to care for themselves, despite the fact that having developmental disabilities made this impossible.

In the two homes which were visited it was observed that mothers and siblings of the adolescent with intellectual disability provided physical care and social support in the form of companionship, and emotional support. It was noticed that parenting styles in the two homes differed with one mother being authoritarian and neglectful while the other one was over indulgent [16]. Both adolescents did not have peers to visit or play with them from the neighbourhood.

CONCLUSION

Adolescents with ID have normal emotional feelings which are satisfied through appropriate social relations with a variety of individuals in their immediate environments. However, they tend to experience challenges in forming and maintaining social relationships with peers in the areas that surround their homes. As a result their mothers and siblings keep them company most of the time. The study has also noticed that transitional services into adolescence and young adulthood are absent.

RECOMMENDATIONS

There is need for a coordinated national strategy for the prevention and amelioration of intellectual disabilities as well as transition into adolescence and adulthood services in Zambia.

Interventions can be made using 'A Model for Parental Involvement' which has been adapted from the work of Kroth, (1985) and Lombana (1983) cited in [17]. It is an intervention model that involves parents in the care of their children with disabilities within their home environment. The model uses major strengths and needs that parents have and is therefore ideal in cases where there is shortage of specialized professionals.

ACKNOWLEDGEMENTS

Many thanks go to my two research assistants; Mr Chole Musonda and Ms Getrude Tembo who are field staff for Archie Hinchcliffe Disability Intervention. Special thanks to the two translators, special education teachers at Bauleni Special School, Ms. Esther Tembo and Ms. Grace Banda for their determination in translating and transcribing the data. Finally, my thanks go to my husband Javan Nkhosi for his untiring encouragement and support during the research project.

REFERENCES

1. American Psychiatric Association. (2000). Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision. American Psychiatric Association. Washington D.C. p 43
2. Berney, T. & Allington-Smith, P. (2010). Psychiatric Services for Children and Adolescents with Intellectual Disability. College Report CR 163. Royal College of Psychiatrists. http://www.rcpsych.ac.uk p 12
3. Cormack, M. F. K., Brown, C., & Hastings, P. R. (2000). Behavioral and emotional difficulties in students attending schools for children and adolescents with severe intellectual disability. Journal of Intellectual Disability Research. Retrieved on 10th July, from pp 124–129
4. Serpell, R. & Nabuzoka, D. (1989) Assessment as a guide to meeting the needs of rural Zambian families with a disabled child. Psychology Department, 29 ps. (mimeo) (Paper presented in a symposium on "sociocultural context and childhood disability" at the 10th Biennial Meetings of the International Society for the Study of Behavioural Development (ISSBD), Jyvaskyla, Finland: July 1989).
5. Burns, N. & Grove, S. (1997). **The Practice** of Nursing Research Conduct, Critique, & Utilization. 3rd Edition. Philadelphia: W. B. Saunders Company pp 543-545
6. Paas, S. (2013). Chichewa/Chinyanja English Dictionary Mtanthauziramawu. (4th Edition). Blantyre: Claim Mabuku pp 739 - 1055
7. Emerson, E., & Hatton, C. (2007). Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: a replication. Journal of Intellectual Disability Research Retrieved on July 15th, from http://www.library.wiley.com/journals/101111/(issn)1365_2788 pp 866–874
8. Bronfenbrenner, U. (1994). Ecological Models of Human Development. International Encyclopedia of Education, Vol 3, 2nd Ed. Oxford: Elsevier pp 1643-1647

9. Karra, A. (2013). Social Skills of Children with Intellectual Disability attending home based program and Children attending regular special schools – A Comparative Study. International Journal of Humanities and Social Science Invention ISSN (Online); 2319 – 7722, ISSN (Print): 2319 – 7714. http://www:ijhssi.org Volume 2, Issue 8, pp 59-63
10. Totsika, V., Richard, I., P., & Hastings, 1., et. al. (2011). A population-based investigation of behavioral and emotional problems and maternal mental health: associations with autism spectrum disorder and intellectual disability. Journal of Child Psychology and Psychiatry (52)1 pp 91–99 http://www/doi:/ 10.1111/j.1469-
11. Keller, H., Borke, J., Staufenbiel, T., et. al. (2009). Distal and proximal parenting as alternative parenting strategies during infants' early months of life: a cross-cultural study. International Journal of Behavioral Development, 33 (5), pp 412-420
12. Morris, S., Silk, T. S., Steinberg, L., Myers, S. S., Robinson, L. R. (2009). The Role of the Family Context in the Development of Emotion Regulation. National Institute of Health Public Access Author Manuscript. 16(2), pp 361-388. Retrieved on 1st August from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2743505/
13. Blacher, J., Neeceb, L. C., and Paczkowski, E. (2005). Families and intellectual disability. Current Opinion in Psychiatry (18) pp 507–513.
14. Tsai, S.-M. & Wang, H.-H. (2009). The relationship between caregiver's strain and social support among mothers with intellectually disabled children. Journal of Clinical Nursing, (18) pp 539–548. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2008.02524.x
15. Todd, S. & Jones, S. (2003), 'Mum's the Word!' Maternal Accounts of Dealings with the Professional World. Journal of Applied Research in Intellectual Disabilities (16) pp 229–244. http://onlinelibrary.wiley.com/doi/ 10.1046/j.1468-3148.2003.00163.x
16. Baumrind, D. (1991). The influence of parenting style on adolescent competence and substance use. Journal of Early Adolescence, 11(1) pp 56-95.
17. Mitchell, D., Brown, I. R. (1991). Early Intervention Studies for young Children with Special Needs. London: Chapman and Hall pp 215-218