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CHALLENGES AND PSYCHO-SOCIAL NEEDS OF PARENTS OF CHILDREN WITH DISABILITIES AT TOSE RESPITE CARE HOME IN ZIMBABWE

Leonard Mpezeni¹ & Phillipa Mutswanga²

¹Department of Psychology, Zimbabwe Open University Harare, Zimbabwe. ²Department of Disability Studies and Special Needs Education, Zimbabwe Open University Harare, Zimbabwe.

- ABSTRACT

The birth of any child is filled with hope and enthusiasm which is short lived if the child has a disability. In the African context, children represent the satisfaction of social and cultural expectations. Children symbolize the unification of different ancestral spirits and the continuation of the family name and culture, thus the birth of a child with a disability disappoints most of these expectations and purposes. The cause of a child's disabilities is attributed to witchcraft or anger on the part of the ancestral spirits. One or both the parents is viewed with suspicion and blamed for causing misfortune on the family through adultery or witchcraft. This study investigated the challenges that parents and guardians of children with disabilities faced in Zimbabwe. Structured interview guides were administered to a purposively sampled sample of parents and guardians at Tose Respite Care Home in Harare, Zimbabwe. The study revealed that there was a great need of assisting parents and guardians of children with disabilities in the form of material as well as psychological support. The role of counselling was noted to be beneficial to ensure that parents share their experiences in dealing with the challenges that they face. Recommendations made from the study include the creation of a support group of parents at the respite care home was advocated as it can go a long way in ensuring that their needs are addressed. KEY WORDS: Children with disabilities, Parents of children with disabilities, Respite, Psychosocial counselling, TOSE Respite Care Home, Zimbabwe.

💉 Leonard Mpezeni & Phillipa Mutswanga

INTRODUCTION

The birth of any child is filled with hope and enthusiasm which is short lived if the child has a disability. In the African context, children represent the satisfaction of social and cultural expectations. Children symbolize the unification of different ancestral spirits and the continuation of the family name and culture, thus the birth of a child with a disability disappoints most of these expectations and purposes. The cause of disabilities is attributed to witchcraft or anger on the part of the ancestral spirits. One or both the parents is viewed with suspicion and blamed for causing misfortune on the family through adultery or witchcraft. The present study seeks to investigate the role of psycho-social counselling to parents of children with disabilities at TOSE Respite Care Home.

BACKGROUND TO THE STUDY

The term 'Disability' is defined by the World Health Organization as 'any restriction or lack of ability to perform an activity in a manner within a range considered normal for a human being' WHO, 1996). In Zimbabwe, the Zimbabwe Disabled Persons Act of 1996 goes a step further by defining a disabled person as 'a person with a physical, mental or sensory disability, including a visual, hearing or speech disability, which gives rise to physical, cultural or social barriers inhibiting him from participating at an equal level with other members of society in activities, undertakings or fields of employment that are open to other members of society' (Zimbabwe Government 1996:51) .The World Health Report of 1996 states that disabled people constitute 10% of the world's population, (WHO,1996). In Zimbabwe, the Zimbabwe Inter-Censal Demographic Survey of 1997 recorded a total of 218,421 people with disabilities in the country which is about 2% percent of the population (Choruma, 2007). It can thus be noted that people with disabilities are a minority not only in Zimbabwe but also the world.

Within the context of the family, having a child with a disability brings several challenges for the parents, the other siblings and the extended family. The birth of any child into a family triggers many changes within the family set up and well-being. Changes that the family has to come up with include changes regarding sleeping routines, the impending utmost caring attitudes towards the new baby and the unfulfilment of several expectations, (Santrock, 1998). Parents often encounter challenges as they try to come to terms with the results of unfulfilled

expectations of having a child with no disability. Hardman, Drew, and Egan (1984) assert that the birth of an infant with disabilities is likely to alter the family as a social unit. Psychologically the family is affected due to the nature of the disability and the way that each parent views the child's disability. The family is also affected financially as the child has to be periodically checked to ensure that he/she develops both psychologically and physiologically.

Charema (2009) argues that parents of children with disabilities in Zimbabwe are affected psychologically as children are seen as a form of social insurance with regard to the needs and wellbeing of past generations. The family cannot fulfil this expectation as this social insurance cannot be achieved if there is a disabled member within the family, (Mwamwenda, 1994, Mpofu 2001, Chimedza and Sithole, 2000). Parents and siblings usually react with shock, disappointment, anger, depression, guilt and confusion. The confusion and shock is usually brought about due to the practical problems in the management of a child with a disability. Due to these challenges parents may consult professionals, doctors, traditional healers, counselors, specialist physiotherapists, teachers, audiologists, psychologists, and other professionals searching for treatment, correction, and any other help that they can obtain in aiding them to raise their child,(Hardman et al, 1993). In Africa, traditional healers and diviners are given more preference over other professionals like counsellors, medical doctors or physiotherapists. It thus becomes a challenge for these professionals to offer their services to individuals who need their help but do not seek it.

The provision of basic services and human rights assistance in Southern Africa and in Zimbabwe are provided by government departments, local voluntary organizations as well as other external development agencies. The Department of Social Welfare in the Ministry of Public Service, Labour and Social Welfare is the government department that is responsible for disability issues in Zimbabwe, (Chimedza, 2001). The department as well as all the other organisations that are involved in the provision of services and assistance programmes are guided by the Disabled Persons Act of 1996.

STATEMENT TO THE PROBLEM

Parents of children with disabilities face many challenges ranging from the social, economic and psychological problems. A child with a disability is often viewed as a burden both by the family and

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the whole society at large. These problems are exacerbated by negative cultural attitudes which persist not only in the community, but also among family members. Disability issues within African contexts continue to be associated with maternal wrongdoing, witchcraft and evil spirits (Charema, 2009).

The challenges and psycho-social needs of parents of children with disabilities who are within respite care homes and those that outside these homes are slightly different. This is due to the different scenarios' that exist regarding the caring and welfare of these children.

CULTURAL MISCONCEPTIONS ABOUT THE DISABLED WITHIN AFRICAN CONTEXTS

Africans are generally noted to have positive attitudes toward child bearing and parenthood, (Ipaye 1982) and (Mwamwenda 1994). The emergence of any pregnancy is greeted with jubilation and expectations, thus every pregnant woman expects a full term and healthy baby. Consequently, she is shaken if the child is born with a disability and that the occurrence of disability at any stage after birth conveys some form of resentment, bitterness, anger, fear, emotional stresses, to the family of the baby in general and in particular the parents whose pride is greatly affected. In traditional African societies, people viewed the presence of a disabled person in a family as an indication that someone in that family had sinned seriously against God. As a result of such thinking, the disability was some form of punishment to the family. Disabled children formed a segment of the population that was generally looked down by the 'normal citizens'. In most African societies these individuals neither had a say in the administration of societies nor did they contribute towards its progress through the paying of taxies or levies, (Denga, 1986).

According to Ansah-Yamoah (1986), in traditional Nigerian societies especially in the Western parts of the country, they believe in the concept of re-carnation and that a disabled person is viewed as a wicked person whose body was mutilated during a previous life. In such instances, a thief or a witch that might have been stoned to death can be reborn with malformed limbs or scars on the body. In the Southern part of Nigeria, it is argued that certain tribes indiscriminately exterminated their congenitally disabled children by suffocating them to death at birth or sacrificing them

to the gods or spirits of the ancestors to appease them. Within the Zimbabwean context, issues of disability and conceptions of disability are often influenced by socio-cultural beliefs, assumptions, myths and fears (Choruma, 2007). The way people with disabilities are viewed is also illustrated when one views the language notations that address people with disabilities. Kabzems and Chimedza (2002) assert that in Shona there are 21 noun classes each with a specific prefix. Nouns referring to people and indicating kinship usually begin with the prefix muin the singular (Noun Class 1). The most commonly used nouns referring to people with disabilities use the prefix chi- in the singular (Noun Class 7). These noun classes are normally used for objects and when used with humans are considered pejorative such as drunkard (chidhakwa), dumb person (chimumu) and cripple (chirema). It can be noted that in Zimbabwe that viewing individuals with disabilities as 'incomplete' permeates society through the language that is used, thus the understanding of traditional beliefs and related practices about disability within a specific socio-cultural context is vitally important.

The birth of any child into a family usually triggers many changes within the family set up and well-being. Challenges include the changing sleeping routines, the impending utmost caring attitudes towards the new baby and the fulfilment of several expectations, (Santrock, 1998). Hardman, Drew, and Egan (1984) assert that the birth of an infant with disabilities is likely to alter the family as a social unit in a variety of ways. In an extensive survey of the factors that influence families that have children with disabilities Travis (1986) pointed to several factors that are considered when it comes to weighing the family burden and they include sleep disturbances the child's disability might cause the parents, Physical burdens related to dressing, lifting, feeding and so on that an illness or disability might create for the parents. Other challenges include complicated diets which require extra time when preparing as well as extra housecleaning which might be necessary. Issues of financial stress also strain the abilities of the whole family in terms of sourcing what the child with a disability requires as well as supporting all the other children within the family. Turnbull and Turnbull (1990) also assert that challenges also emanate from the adaptations that may be needed in housing and furnishings as well as the unpredictability of the disease or disability.

p - *ISSN* : 2349 - 0187 *e* - *ISSN* : 2347 - 9671

Research into reactions of family members of children with disabilities is extensive, but the focus of this section of the literature review will be to highlight the need to support parents through this difficulty journey. This discussion will start with a discussion of the effects of having a child with any form of disability in the family. This includes feelings experienced by the family with the child with a disability and the behaviours that emanate from these feelings.

An overview of the feelings experienced by the family of children with disabilities will be presented next. The following lists of feelings were identified by Greenspan, Wieder and Simons (1998), though other researchers have also identified these feelings as they occur during various stages of adjustment. The contribution of other researchers is included as it relates to the point in question. In their study on the psychological characteristics of mothers of children with disabilities in South Korea, Yim, Moon and Yung Lee (1996) found out that the mothers of children with disabilities suffered from serious psychological distress in the initial diagnosis of the child's disability. Psychological distresses included somatization, depression, anxiety, hostility and phobic anxieties.

It can also be noted that these psychological distresses at the initial stage of diagnosis may distraught the mothers emotionally as they may lack the proper initiative to take care of their children, which may have significant impacts on the development of their children. Yim et al (1996) also found that the severity of the child's disability had little influence on the degree of the mother's initial psychological distress. In other words there were no significant differences in terms of psychological distress between mothers assessed at initial diagnosis and those assessed later in the child's development. Yim et al (1996) also found that psychological distress is usually not resolved even after several months after diagnosis and thus there is a great need for psychosocial counselling to ensure that the mothers of children with disabilities can cope with the stresses of caring for a child with a disability.

This study was guided by the following research questions: (a) What are the psycho-social needs of parents of children with disabilities at TOSE Respite Care Home? (b) What is the nature of support that is offered to parents of children with disabilities (c) What are the reasons for not receiving any kind of support despite the need of such support (d) What

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other challenges do parents of children with disabilities face in taking care of their children despite respite care efforts

METHODOLOGY Research Design:-

This study employed a case study research design. This method was used as the researcher felt it was the most ideal for the study. A case study research design is an intensive description and analysis of a single individual or organization or event based on information derived from different sources such as documents, test results and archival records, (Christensen, 1994). Since the study concentrated on TOSE Respite Care Home which is an organization the case study design was used by the researcher so as to note the challenges that parents of children with disabilities resident at the home faced. In addition, this research design suits the context under which the present study were taken as the survey represents a probe into a give state of affairs that exist at a given time. It therefore means that direct contact was made with the individuals whose characteristics, behaviours, and issues were relevant to the investigation under study.

Population:-

The study population consisted of parents and guardians of children with disabilities who are resident at TOSE Respite Care Home. The parents and guardians that were part of the study population are those parents and guardians whose children were at the home during the duration of the study. All the parents of children whose children were transferred or were not at the home when this study was carried out were not part of the study population. **Sampling:-**

A total of 10 Parents and guardians of children with disabilities at Tose Respite care Home were randomly selected from the students register and invited by letter to participate in the study. Permission to undertake the study was given by the Home's Board of Directors. Parents were assured that they would not be identifiable from interviews and that any potentially identifiable features would be removed from the transcript.

Data Collection Instruments and Procedures:-

Data was collected through the use of questionnaires and in-depth interviews in which parents of children with disabilities. The researchers preferred the use of interviews as they allowed the parents to fully explain their views and also allowed the researcher to probe on unclear assertions.

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Data analysis:-

The data that resulted from the interview was analysed manually. Similar ideas were identified and grouped into thematic a category, that is themes were put into categories based on the meaning they conveyed.

Ethical Considerations:-

All the necessary ethical considerations were taken into account when this study was conducted like seeking permission the home's Director and that respondents involved in this research were guaranteed of confidentiality. Individual names were not used and the participants were not required to sign their names when answering the questionnaires or being interviewed, this was done as some of the aspects on the questionnaire were an intrusion into the respondent's lives. The parents' consent was sought and that they were given the option to withdraw from the research study at any point. Parents were assured that they would not be identifiable from interviews and that any potentially identifiable features would be removed from the transcript.

RESULTS

The findings in this study revealed four dominant themes. The first theme centred on the parents' psychosocial needs in caring for their children with disabilities. The second theme discovered the nature of support that is offered by family members and friends. The third theme illustrated the reasons parents and guardians perceived as hindering their efforts of receiving any form of support. The final theme showcased the challenges that parents and guardians faced in taking care of their children with disabilities.

The psycho-social needs of parents of children with disabilities (n=10)

There were general perceptions regarding the psychosocial needs of parent of children with disabilities at TOSE Respite Care Home. The participants felt that there was a need of social support among friends and family members. This emanated from the desire for recognition of the fact that despite giving birth to a child with a disability they were still 'normal' human beings. The need for counselling services that is aimed at addressing the stigma that they experience from members of the society, friends, family members and other health professionals who are meant to assist them in various ways.

The responses gathered indicate that most of the respondents thought that they needed

counselling as a way of alleviating some of their challenges. One of the respondents had this to say:

'My wish is for us to find time so that we can sit as parents and are counselled pertaining our challenges. At times we just need someone to talk to just like what you are doing right now, even if you do not provide us with anything but just having someone to listen to your problems'

Another parent also aired the same concerns:

'We need counselling because people see us as a cursed people because of our children. It really stresses me sometimes'

It can be noted that parents and guardians expressed several psychological needs that they felt were important to them as parents/guardians of children with disabilities. The issue of counselling was expressed as a vital component of the parents' wellbeing and psychological makeup.

Nature of support that is offered by family members and friends (n=10)

The study noted that most of the parents and guardians of children with disabilities received little support from family and friends. Support was in the form of monetary as well as spiritual support. One of the parents stated the following;

> 'Most of my friends, especially from our church often pray with me concerning the child's disability'

Another parents also stated the following

'I usually get gifts from my siblings; they often give me money to buy medication for the child as I am not employed'

Parents and guardians noted that the most significant support was usually from friends and family. The most significant form of support was financial and spiritual support. It can be noted that to the parents and guardians, support in the form of counselling was usually given through church members through social and spiritual support.

REASONS FOR NOT RECEIVING ANY FORM OF PSYCHO-SOCIAL SUPPORT

The majority of participants stated that they perceived that they did not receive a lot of psychosocial support from friends and family due to the nature of their children's disabilities. Some of the relatives thought they were cursed hence didn't want to be associated with them. One of the participants stated the following;

p - *ISSN* : 2349 - 0187 *e* - *ISSN* : 2347 - 9671

Relatives usually shun my home as they feel that we are a cursed family, even my old friends no longer visit me ever since I gave birth to this child'

The participants also argued that the harsh economic environment that Zimbabwe was facing also meant that others were also facing challenges in catering for their own needs. It was thus very difficult for others to cater for their own families as well as assisting others. Of the few that receive some form of support, they stated that this support came mostly from relatives from their maternal parents. Maternal grandmothers offered support in the form of spiritual and social support which can be equated to counselling and was aimed at handling the disability. It can be noted that maternal grandmothers may have given support to the family of a disabled child primarily to support their daughter who carried the blame of giving birth to such a child.

Challenges that parent/guardians face in taking care of their children (n=10)

The participants stated that they faced several challenges in taking care of their children due to the nature of their disabilities. The following challenges were noted;

- Challenges in raising the fees, especially those that are unemployed and rely on financial assistance from members of the family and other sympathizers.
- Emotional challenges regarding the future of the child which seem to be very bleak. This causes the parents to have sleepless night as they ponder on the chances that their children have.
- Concern over the children's health issues is another recurrent challenge that parents face. They often dread the calls that they receive from Tose Respite Care Home as they always fear for the worst regarding the children's health issues.
- Lack of acceptance among family members and relatives. Most parents expressed that they are social outcasts due to their children's disability.
- Most parents felt that they were not competent enough to take of the children when they came for school holydays. They are not able to assist the children in exercises and other physiotherapeutic techniques.

💉 Leonard Mpezeni & Phillipa Mutswanga

Parents expressed that within their homes they usually cannot give the children enough food when they come for school holydays. This meant that they usually deteriorate when they are at home due to lack of food.

Perceived parent's perceptions on the solutions of overcoming the challenges that they face (n=10)

The parents/guardians perceived that there were several solutions to the kind of challenges that they faced. The following are some of the suggested solutions that they perceived would be able to solve the challenges that they face in taking care of their children with disabilities;

- Assistance in fees from members of the Donor community.
- The availability of a fully equipped clinic facility at Tose Respite Care Home with competent staff of a nurse and a visiting Doctor who has the responsibility of treating children as and when diseases occur.
- Formalized counselling sessions should be provided at the Respite facility to cater for parents' emotional needs.
- The unemployed parents felt that they wanted the government to provide them with employment so that they can a decent living for their children with disabilities.

The parents and guardians of children with disabilities at Tose Respite Care Home had several recommendations that they perceived as important in meeting the challenges that they face. The main recommendation was that there was a need for formalized counselling for parents at Tose Respite Care Home so that their challenges can be alleviated.

DISCUSSION

This study describes the challenges and psycho-social needs of parents and guardians of children with disabilities at Tose Respite Care Home in Harare. The use of the qualitative approach enabled potentially sensitive issues to be discussed in depth, and illuminated the challenges and the psychosocial needs of parents of children with disabilities in Zimbabwe.

The present study found out that the challenges of parents of children with disabilities ranged from both the social to the psychological aspects that are related to the caring of children with disabilities. The parents of children with disabilities face challenges in the sourcing of funds and also in socializing with other parents whose children have

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no disabilities. According to Margonwe and Mate (2007) as cited by Lang and Charowa (2007), the literature on the subject of parents of children with disabilities state that parents of children with disabilities face many challenges in the caring of their children. It can also be noted that as was identified by earlier studies in the area of parents of children with disabilities, parents of children with disabilities have low self esteem which hinder their participation in many social activities, this is probably due to the disabilities that their children have. The present study also concurred with Santrock (1998) who argued that the birth of a child with disabilities within a family triggered several changes in a family.

The present study found out that parent's expressed the need for periodical counselling sessions that are aimed at assisting them to cope with the challenges of having a child with a disability. Most parents stated that there is a great need for the respite facility to come up with programmes that are aimed at counselling parents on various issues that relate to their children's disabilities. Charema (2009) also illustrated the beneficial aspects of counselling for parents of children within African contexts. The need for counselling to parents of children with disabilities is supported by many studies on parents of children with disabilities.

The use of counselling among parents of children with disabilities is also supported by Ziolko (1991) who did an extensive review of the literature of counselling parents of children with disabilities. As argued by Greenspan et al (1998), counselling must be 'part of the package' that parents of children must be given where ever they are assisted. It can thus be noted that periodic counselling is needed as it allows parents and guardians to cope and manage their children's disabilities.

The present study also found out that while most parents received support from various individuals, they still perceived that they were not getting enough and attributed this to factors related to cultural myths and the general conceptions of children with disabilities and their parents as well as extended families. Margonwe and Mate (2007) as cited by Lang and Charowa (207) reviewed several studies on disability issues in Africa and noted that parents of children with disabilities expressed the need for support and welfare as taking care of a child with a disability is an expensive exercise. It can be argued that any kind of support to parents of children with disabilities is important as it relieves pressure on the parent and also encourages the eradication of stigma that is associated with having a child with a disability.

It must however be noted that while most of the findings of the present study were in line with other general outcomes of studies on disabilities, some findings might be only peculiar to this study as this study was carried out with parents of children with disabilities that are resident at a Respite Care Home only. Data obtained from this sample might not be generalised to other institutions that cater for children with disabilities in Zimbabwe or any part of the world although some of its aspect maybe used in other studies as supporting evidence or otherwise.

CONCLUSION

The parents and guardians of children with disabilities at Tose Respite Care Home considered the establishment of the centre as a very noble gesture because it helped them see their children in a more positive lense than before. The study proposed counselling of both parents and their children with disabilities as an essential and necessary activity that could enhance their livelihoods. It was also considered as an essential empowerment. The majority of parents with children with disabilities informally suggested that it would be good if Zimbabwe could have more people as the founder of Tose Respite Care Home with the willingness to establish such centres for the rural communities. High appreciation of the establishment of more such centres in both urban and rural areas was expressed because it helped society see children with disabilities as capable equal contributors to development and as equal beings too.

RECOMMENDATIONS

From the above findings and conclusions the following recommendations were made:

- That counsellors in Zimbabwe render counselling services at the centre as community service
- There was need for more founder members to develop such centres in both rural and urban centres
- That the government adequately subsidised such centres through cash and kind and psycho-social support to parents with children with disabilities and their children
- That individuals in society support the parentless children, orphaned and those with serious financial constraints by inviting

p - *ISSN* : 2349 - 0187 *e* - *ISSN* : 2347 - 9671

some of these children from the centre for holidays and weekends to fill in the felt family or needs gaps

- That Group Counselling be employed to allow parents or guardians with children with disabilities learn from each other's circumstances with a view that would help them come to terms with their various situations
- There was need for more volunteers from the health field in form of medical examinations and provision of medication to children with disabilities with prescribed life medications
- ☆ That the government provided nutritional support to such centres
- That picture of successful children from the centre be displayed at main entrances with a view to communicate that disability does not mean inability and that would help eradicate stigmatisation and discrimination of such children.

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