A PHENOMENOLOGICAL APPROACH TO THE CHALLENGES FACED BY PARENTS OF CHILDREN WITH DISABILITIES IN SWAZILAND

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Abstract

Parenting a child is a challenging experience let alone parenting a child with a disability. The nature of the disability in a child goes with its complexity and it often puts parenting skills to the test. This study explores the experiences of parents of children living with disabilities. A phenomenological framework and research design, which employed the focus group discussion and individual interviews, was chosen to collect data. Non-probability criterion purposive sampling procedure was used to select parents of children with disabilities from the three special schools. The sample size comprised 48 parents of which 36 took part in the focus group discussions (FGD), while 12 were individually interviewed. Content analysis was employed to make sense of the data. Peer review and member check were followed to improve trustworthiness. The themes that emerged revealed that parents had unique experiences in raising their children with disabilities; and, the necessity for parents to have appropriate information about the disabilities of their children. It was evident that such parents require counselling support to enable them to deal with the complexities that emanate from living with a child with disability. The authors recommend that Government should consider enforcing policy to check the rise of disabilities in Swaziland.

Keywords: Child disability, Counselling services, Parental constraints, Parenting skills, Policy intervention, Swaziland

Introduction

The purpose of this study was to gain a deeper understanding of the lived experiences of Swazi parents of children with disabilities by exploring the challenges they everyday face when trying to participate in their children's lives. Studies have noted the different categories of disabilities that may developmentally manifest in some children (Neeraja & Anuradha, 2014). These disabilities have been categorized in various forms including: developmental and speech disorders (Neeraja & Anuradha, 2014); Social and emotional disorders (Ferguson, 2014); and Social skills deficit disorders (Leach, 2015). Others may include: dyspraxia and auditory perceptual deficit (Barrow, 2017); academic skills disorders (Mackelprang, 2010); visual perceptual deficit; behaviour and adjustment problems (Neeraja & Anuradha, 2014). The list of these disabilities found in children is acknowledged here as non-exhaustive.

Nonetheless, as parents learn that their child has a specific disability, they begin a journey that takes them into a life that is often filled with strong sentiments and difficult choices (Taderera & Hall, 2017: 1). Gona, Newton, Rimba, Mapenzi, Kihara, Vijver and Abubakar (2016) have acknowledged that the challenges faced by parents of children with disabilities are less reported by African scholars. Instead, the authors note that most of what is reported on the challenges confronting parents of children with disabilities were mainly based on research conducted in Australia, Europe, and North America (Gona *et al.*, 2016). This view is supported by Taderera and Hall (2017) who note that majority of research conducted on the impact of child's disabilities on the family has been based on Western experiences, with less attention paid to the African research context.

Notwithstanding the above claim, numerous research note that living with a disabled child can have profound effects on the family; particularly the parents (Leach, 2015; Matenge, 2015; Ceka & Murati, 2016). Parents of children with disability experience a sense of grief, loss, and anger as they learn of their child's diagnosis (Neeraja & Anuradha, 2014). Gona *et al.* (2016: 2), report that "the stress of living with a child with [disability] can affect the psychological and emotional wellbeing of parents and generate conflict between them". Having a disabled child in the family tends to divert the attention of parents particularly the mother from other aspects of the family management (Elford, 2014). Moreover, having a disabled child in the family puts a lot of pressure on the parents' allocation of time and financial resources to their healthy and unhealthy children (Ferguson, 2014). The situation further puts a lot of strain on the parents' parenting practices (Heer, 2012).

A study by Thwala, Ntinda & Hlanze (2015:210) revealed that parents with a disabled child at home are confronted with challenges relating to "social isolation, emotional stress and depression, grief and financial problems". Reeja and Sujatha (2013) study of the lived experiences of mothers of children with Down's syndrome in school in Mangalore revealed that the mothers were extremely challenged by the worry about the unpredictable future of their child. Yet, more studies have reported further challenges for both parents of a child with disability. Taderera and Hall (2017) report that having a disabled child in the house may lead to a breakdown in the couple's relationship, which may lead to a divorce. Taderera and Hall (2017: 3) further note that "marriages may fail because of accusations of evil spirits when a child with any form of disability is born" into a particular household.

Stigmatization has also been highlighted in research to constitute a huge challenge for parents of a child with disability. According to Gona *et al.* (2016: 2), "stigma is one of the difficult aspects of public encounters experienced by parents of children with disability". Research further notes that that such stigma is exacerbated by the religious and cultural beliefs within traditional societies. Thus, "African indigenous religions explain the world in a context of interaction between various natural spirits…problems and disharmony in life often means two or more spirits are in conflict" (Taderera and Hall (2017: 3).

In a study by Okeke and Mazibuko (2014: 14), the findings revealed that parents of children with disabilities "had the challenge of providing basic needs for their children". Furthermore, Okeke and Mazibuko (2014) showed that parents who took part in the study were hugely challenged by their level of education. Lack of basic information was one of the effects of this lack of education. As a result, most of these parents stayed away from the schools attended by their children, even when invited to discuss the welfare of their children, those parents stayed. An earlier study by Barbosa, Chaud and Gomes (2008: 47) revealed that "healthcare professionals are often are often unprepared to give the diagnosis of disability to the family, which makes this a traumatising moment for the parents". The situation in which parents fail to receive adequate support from healthcare professionals in managing their child with disability can further complicate the challenges already faced by the affected parents. Barbosa *et al.* (2008) further highlight that the knowledge of the disability of one child can have a multiple effect on the family life, particularly that of the mother.

As studies have pointed out in this and many other papers, it would then appear that the birth of a disabled child in a family, presents a disorganising experience for the entire household. The family life is emotionally unbalanced as it suffers real changes. Given this scenario, understanding the challenges Swazi parents encounter as they try to make contributions to the lives of their children with disabilities became imperative for these researchers. The researchers thought that such research would enable contribution to the knowledge on how the society in general can support them to effectively participate in the daily lives of their children with disabilities. Despite the potency of empirical evidence in this regard, it is however, unclear as to what kind and quality of information that is available about the challenges that Swazi parents live through, or the support they need to enable them to effectively participation in the lives of their children with disabilities going forward. Moreover, it is important for research to unearth plausible empirical evidence that can impact policies on effective support and intervention strategies for families with children having disabilities.

Objectives of the Study

The primary goal of the study was to explore and describe the experiences of Swazi parents of children living with disabilities. Specifically, the study sought to:

i. conceptualise the type of disabilities Swazi parents experience among their children;
ii. explore and to describe the types of challenges that confront the parents of children with disabilities;
iii. establish how the parents of these children cope with the challenges;
iv. understand whether these parents receive any form of support and from who and, finally make recommendations that may implicate policy and practice directions going forward.

Method

A Phenomenological Framework

The qualitative research approach followed in this study. Creswell (2009) defines qualitative research as an inquiry process of understanding, based on distinct methodological tradition of inquiry that explores a social or human problem, where the researcher builds a complex holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting. Given this approach, the choice of the phenomenological framework provides opportunity to obtain information about how individuals participating in a particular research, experience the phenomenon under investigation (Matenge, 2015).

Phenomenology was thought appropriate as the framework appears to be in line with the primary goal of the study, which was to investigate and describe the lived experiences of Swazi parents of children living with disabilities. The approach is also thought appropriate because it only investigates real-life experiences (Gona *et al.*, 2016) that are by the way brought about by the reality of parents living with a child with disability in the family. That is why the goal of phenomenological research is to "…gain insight into our human experiences and come into greater contact with the world" (Leach, 2015: 36). By adopting the phenomenological approach, it allowed the researchers to identify parents' lived "experiences within the specific context of their subjective realities, and with this understanding the authors developed and presented interpretations of these experiences in the results and discussions sections of this paper.

Selection of Participants

The target population for this study was parents of children living with disabilities from who attended the three special schools located in three of the four geopolitical regions of Swaziland. The rationale for choosing parents from the three special schools was because of the diversity of the disabilities catered for in these institutions. One of the institutions caters for the physical, intellectual and visual impairment. The second institution caters only for the intellectual disabilities. While the third institution focuses on hearing impairment. The target population was thought to be appropriate because parents with different experiences and challenges were needed for the research study. The sample size comprised 48 parents, drawn through the nonprobability criterion purposive sampling procedure. The criterion purposive sampling allows qualitative researchers to select particular participants because they are believed to be sufficient to provide maximum insight and understanding of the phenomena under investigation (Schumacher & Macmillan, 2010; Thwala *et al*., 2015). The strength of the criterion purposive sampling is that the researchers were able to use their judgment to select a sample they believed would provide the required empirical data (Reeja & Sujatha, 2013).

Instrumentations

In line with phenomenological studies, empirical data used in this study were obtained by way of the focus group discussions (FGDs) and the semi-structured individual interviews. The FGD was adopted because it enabled the researchers to obtain data or information from a group of participants to supplement information from the individual interviews. Furthermore Cohen and Manion (2005) opine that focus groups are especially useful when time is limited and that people feel more comfortable talking in a group than alone. Interaction among participants may be more informative than with individually conducted interviews. In addition, as a method of collecting data, the FGD is economical even in terms of finance (Schumacher & Macmillan, 2010). In the focus group interviews, similarities or differences in the parents' experiences as they raise and nurture their children with disabilities were extracted. Two focus group discussions were conducted in each of the three participating schools, and each group comprised six participants. A focus group guide comprising of 10 questions, which had themes with specific key issues were used to facilitate the FGD processes and each session lasted for 2 hours.

A semi structured face to face interview was used to acquire in-depth information about the experiences and challenges parents faced in raising and nurturing their children with a disability. In each institution four parents participated in the individual interviews. The purposeful random sampling was used to further select the participants for the individual interviews. Open ended questions were used to get direct quotations from the parents about their experiences, opinions, attitudes, feelings and knowledge. More time was given to discuss topics in detail and gain in-depth personal accounts. The researcher audio recorded all interviews to capture the exact words of participants, which helped in adding richness to the data being collected. The interviews enabled the researchers to get an understanding of the person's behaviour through eyes and voices. Interviewees were engaged in a setting that was relaxed and familiar to them. The duration of the interview varied on an individual basis, thus each interview took about 40 minutes to 1hour. And an interview guide was used to direct the flow of the interview interaction. Both the interviews and FGDs were tape recorded.

Data Analysis Procedure

The goal of this phenomenological research on the challenges facing Swazi parents of children with disabilities is to uncover fundamental themes that will help to describe the meaning behind the parents' lived experiences. The four "fundamental life world existentials [namely], lived time, lived space, lived body, and lived human relation were used as a lens to guide analysis" (Elford, 2014: 30). The individual interviews were tape recorded, listened to and transcribed verbatim into Microsoft word document. The researchers then followed a step-by-step approach to discover relevant themes. In line with Matenge (2015: 9), the researchers followed the "inductive thematic analysis…a process that involves observing themes as they emerged from the data without imposing preconceptions and allowing for the organization of themes within the data". Then, the researchers followed a coding process in order to collapse numerous commonalities into categories, which informed the themes that emerged as the results of the study presented in the relevant section below.

Similarly, data from the focus group discussions were analysed thematically as well. The tape recorded discussions were listened to first and all important points as they were presented in the tape were written down. This means that recordings from each FGD were transcribed verbatim into Microsoft word document. Pseudonyms were used for identification instead of the parent's names and to avoid mixing up information. Related information was coded and grouped into categories. Following this, themes and narratives were identified from the categories. The themes and narratives were coded according to the objectives of the study.

Data Credibility

Credibility in qualitative research means methodological soundness, adequacy and degree to which the reports of a particular research are a true representation of what the objectives of the study (Holloway & Wheeler, 2013; Elford, 2015). Credibility in the present research then, refers to the degree by which the results of this study on the challenges faced by Swazi parents of disabled children remain truthful to the parents' experiences of living with a child with disability. To achieve credibility, the researchers engaged in in-depth conversation through the individual's interview and FGDs. The researchers then conducted member checks on the analysed texts and transcripts so that participants are given the opportunity to confirm the authenticity of the reports (Creswell, 2014). In line with Elford (2015: 31), "member-checks were carried out through [cell phone conversations] with participants to share findings and allow participants to verify that meaning was accurately captured". Most importantly, the researchers remained reflexive throughout the research process, which enabled them to objectively obtain and report the findings of the study.

Ethical Issues

Ethical approval was obtained from the relevant office where the researchers are based. It is then important to note that participants' involvement in the research was voluntary and the researchers clearly explained the purpose of the study to the participants. All participants were made to sign an informed consent letter. To maintain confidentiality and anonymity, pseudonyms or false names were used to replace the participants' actual identities. The researchers were also mindful of the possibility of harm to participants, considering the sensitive nature of issues around disabilities. As a result, the researchers made an adequate attempt to ensure that participants were clearly aware of the objectives of the study. The researcher also explained to them that they were free to cancel the interview at any time they felt uncomfortable. The researcher was also aware that it is possible that some fathers may feel that they had let their children down, should the interviews make them to realise their failures. As a result, the researchers ensured that the participants were adequately counseled before the commencement of the fieldwork interviews and the FGDs. The researchers also left their contact details with the participants should in case they had a need to reach them.

Results

The results of this study are presented based on the various challenges as expressed by the parents who constituted the respondents. The findings generally revealed that parents had so many challenges which affected them in raising their children living with disabilities. These challenges are as follows:

Socio-economic Conditions of the Parents

Poverty featured strongly as a challenge amongst the parent participants. Parents in the study revealed that they were faced with severe socio-economic conditions which were mainly caused by financial constraints in which they found themselves. Thus, the respondents were restricted in their ability to help because of poverty. They were unable to send their children to relevant and suitable schools that can rehabilitate their disabled children. One of the parents noted: "after discovering that our child had autism we decided to enroll him to a rehabilitation centre…[that] was so helpful to the child but the challenges were that we could not afford the required costs per term including transport costs". Chimhenga and Musarurwa (2011) revealed that some parents are unable to meet the high travelling expenses to and from the school since such children would need special transport.

The Choice to Quit Job for the Sake of the Child

Another challenge the parents revealed through both the FGDs and the individual interviews was the bitter choice of having to quit job in order to pay attention to their child needing help. It was evident that some respondents explained that on the issue of work and careers, they decided to quit their jobs for the sake of their children. One respondent revealed that she decided to leave her job and take care of their child. When probed why she stated that it was because she could not find a suitable house maid for him as most of them could not afford to care for the child due to their behaviour problems. Again, Chimhenga and Musarurwa (2011) revealed that in some homes where house maids were employed, children with disabilities did not receive proper care, especially when their parents would have gone to work, the child is sometimes left alone, without food or proper care.

Another respondent concurred with the notion of leaving the job for the sake of their children living with disabilities had this to say:

> *I was working in one of the sugar companies in the Lubombo Region, before finding a place for the child in one of the special schools in Mbabane. I had to leave my job and a promotion in compromise for my son and we had to re-locate in Mbabane for the sake of our son. That was a blow to the family especially on the financial aspect because already my wife had left her job to care for our son.*

Loss of Family Freedom

Another challenge revealed by the parents was lack of freedom on the parents and other siblings. According to Green (2007) parents of children with disabilities often raise their children within the context of a powerful societal discourse that devalues disabilities and they are therefore expected to feel emotionally burdened. The respondents revealed that they devote more time to child care and spend less time in social activities. They also enjoy less active free time than parents of children without any disability. As a result of the demands of caring, mothers of children with disabilities often report role restriction and limitations in pursuing a career. That was evident in the response of one of the parents who said that: "freedom is limited for the sake of the child. Every time, I had to be at home to welcome her back from school. I am afraid to even leave her alone, because of her mental challenge". The parents explained that it was really difficult for them to travel with their children because of their disabilities. Each time they did that, they drew more attention from the public, which made them feel rather emotional.

Effect of Stigmatization and Discrimination

The effect of stigma and discrimination for children with disabilities was revealed as another challenge that the parents had to endure. Parents in the study revealed that society still has not accepted the children with disabilities as part of the members in the society who also have needs like all other people. This scenario appeared to have huge negative impact on the parents of such children. One respondent remarked:

> *My child was once discriminated in church during Sunday school service. I noticed that he was not made to join the other children as they were reciting some verses. Even when the Sunday school choir was called to perform, my child was put aside. Though she could not talk properly but she could have mumbled and followed the other children. I do not forget that day, but I just kept quiet.*

The respondents revealed that it is so hurting to realize that their children are mocked and discriminated by the society. They felt that due to stigmatization and discrimination, their children's social adjustment resulted to isolation or rejection. The majority of the respondents believed that they were the ones most affected by their children's disability in a way that they were always worried about their children's social lives. That was confirmed by one parent who remarked:

> *It is hard for my child to interact or socialize with her peers and to even visit relatives. Each time we pay a visit to our relatives we had to explain a lot about her educational background. That made me decides not to go with her when visiting our relatives.*

Some parents in one of the special schools expressed their bitterness as they realized how their children were treated by the general public including when in public transport. Since they have hearing impairment there is no proper communication and because of lack of understanding on the side of the general public, it leads to misinterpretation and poor relations and services. Most parents of such children decided to accompany them when they go to school. They assist them along the way as they cannot communicate with the general public when they need some services. The parents felt that the society should be sensitized about the different disabilities found in the country and possibly how they need to be treated.

Lack of Knowledge on the part of the Parents

Most of the respondents agreed that they lacked simple knowledge, ideas and awareness about the disabilities of their children, They revealed that they were unable to recognize the disabilities of their children on time due to lack of awareness. This challenge was evident in the parents' response to the issue bordering on their awareness or knowledge about the disability of their child. One of the parents noted: "I did not know that my child had an intellectual disability. That is why it took some years for me to realize that the child needs to be sent to a special school". The findings of the study revealed that most respondents lacked knowledge and information about the disability of their children thus they could not know what was the problem with their children. They expressed their feelings that parents should be made aware about the disabilities that children may face. Some felt that the information could be shared or exposed in televisions or radio broadcast. It could also be shared in the community centres. That could really help the parents because some of them had the feeling that they would even know where to go for the rehabilitation of their children if they were made to be aware of their disabilities.

Service Provision by Association and the Swaziland Government

Related to the issue of lack of knowledge on the part of the parents, was the issue of service provision by association for disabled and by the Government of Swaziland. The participants in the individual interviews indicated that they have neither heard of any associations for disables nor about the services rendered by such associations. Other participants revealed that one member from the Federation Organization of the Disabled People in Swaziland (FODSWA), which is the umbrella body for all the associations was invited by the administration in one of the special schools to address the parents about the services offered by the organization. Parents in the study suggested that it could be beneficial to join hands as parents of the children with disabilities to form a parent to parent support group. Such group could interact and discuss about the challenges they face in raising their children with disabilities, coping strategies and the future wishes for their children.

Parents' Concerns as a Challenge

The participants expressed huge concern about their children's education, finishing school, ability to acquire a profession and have economic independence. Some parents had questions such as: How in the future would their grown up children manage without them? Where would they live? What kind of financial and emotional support would they receive? Would they be able to have families of their own? Participants, however, remarked as part of their concern that as much as they appreciated what the Government of Swaziland is offering, they felt that the government only catered for their children's academic aspect, while neglecting the parents who also needed to be equipped with relevant skills. The participants felt that such supports for parents of disabled children could be achieved through carefully designed special programmes involving other stakeholders. The researchers hope that the results revealed in this article would have implications on how the government responds to the various needs of parents of children with disabilities. These results also enhance our knowledge and understanding of how the parents of children with disabilities endure life as they raise and nurture their children.

Discussions

The main theme of the findings of this study was the desire to explore and describe the lived experiences of Swazi parents of children living with disabilities. That is why phenomenology was thought to be appropriate for the study bin that it provides opportunity to obtain information about how parents who took part in the study experienced the phenomenon of living with their child with disabilities (Matenge, 2015). Within the specific context of their subjective realities, parent participants in the study expressed that their socioeconomic conditions; the choice to quit job for the sake of the child; loss of family freedom; effect of stigma and discrimination; lack of knowledge on their part; the quality of service provision by associations and by the Government of Swaziland; and specific parents' concerns, were some of the challenges they have to live with every day of their lives as parents of children with disabilities.

The participants bemoaned their poor socioeconomic conditions as a huge challenge on their ability to cater for their children. According to the respondents, they were unable to send their children to well-equipped schools that can rehabilitate their child due to lack of finances. Sometimes, the parents noted that they were unable to meet the high travelling expenses due to that some of their children need special transport to and from school or rehabilitation centres. This scenario was highlighted in the findings of a study conducted by Chimhenga and Musarurwa (2011) on educating children with special needs in the African context. Their findings revealed that some parents were unable to meet the high travelling expenses to and from the schools since such children would need special transport. This situation was equally exacerbated by the fact that some of the parents to face the choice to quit their jobs in order to devote more time to the child with disabilities. Of course as noted in a study by Okeke and Mazibuko (2014) to quit ones job, meant that parents of children with disabilities had the challenge of providing basic needs for their children.

A lack of freedom on the parents and siblings was also noted a huge challenge for the parents. According to Green (2007) parents of children with disabilities often raise their children within the context of a powerful societal discourse that devalues disabilities and they are therefore, expected to feel emotionally burdened. The findings of this study further revealed that parents devote more time to child care and spend less time in social activities. They also endure less active free time than parents of children without any disability. As a result of the demands of caring, mothers of children with disabilities often report role restriction and limitation in pursuing careers, which means most of them decided to leave their jobs for the sake of their children.

Stigmatization and discrimination were equally revealed to be constraining the parents' abilities to support their child with disabilities. Most respondents had the feeling that the society had not yet accepted the children with disabilities as part of the members in the society. Both the FGDs and the individual interviews data revealed that parents of children with disabilities had to endure lots of frustration within the community due to the terrible habits of stigmatization and discrimination by the society. This is also supported by Green (2007), who stated that parents of children living with disabilities often raise their children within the context of a powerful societal discourse that devalues disabilities. Under such circumstance, some of the parents may be expected to feel emotionally burdened. The treatment and behaviour shown by some community members against children living with disabilities in the communities made the parents of the victims insecure. This revelation appears to be supported by Gona *et al.* (2016) who note that stigma is one of the difficult aspects of public encounters experienced by parents of children with disability.

A major limitation that the researchers would like to mention here, relates to the sample size used in the study. Although the researchers identified over one hundred and fifty parents of children with disabilities, however, it was difficult to engage all of the parents due to financial constraints as well as the time allocated for the study. Equally important to note, was the fact that some of the parents were from faraway places mainly in the rural areas of the country. This made it difficult for the researchers to reach all of them. The researchers also observed that some of the parents only joined the FGDs rather reluctantly, due to the fact that some of them were not in the position to open up having considered the focus of the study to be too sensitive. Given these limitations, readers are cautioned on any attempt at generalization of the findings of the study.

Conclusions

It is quite obvious that mothers who took part in this study are faced with numerous challenges that may be constraining their abilities to effectively contribute to the education development of their children with disabilities. More research is however, required in order to further our knowledge on the subject-matter. It is recommended that professional counseling services be made readily available. Parents of children living with disabilities in Swaziland need some counseling before and after the diagnosis of their children. This would seem to be relevant especially to assist them with coping with the reality of having a disabled child.

It is equally recommended for parents to form 'parents to parents support groups' for the different disabilities in order to share ideas as they face their situations. This would enable the parents to help one another with strategies on how to cope with the conditions of their children. It may however, require the involvement of other stakeholders such as non-governmental organizations that cater for people with disabilities in Swaziland. This can assist them with socio-economic and professional life skills. It is necessary to provide information to the family members about the child's disability. Organizations for the persons living with disabilities need to make themselves known to the general public through media programs where they state the services they render.

The Government of Swaziland (GoS) must formulate policies and enact laws which will prevent some disabilities occurring due to negligence of parents or harsh conditions faced by the expecting mothers which are major factors in stress development. The GoS has to look into the future of the children and people living with disabilities in terms of providing more vocational institutions which can cater for those who are beyond the school-going age. The GoS should consider adding more relevant teaching and learning materials to aid children with disabilities in the classroom.

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