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Causes of childhood disabilities in a rural South African community: Caregivers' perspective

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Abstract

Childhood disabilities are conditions that affect or are likely to influence the development of children into adulthood. Childhood disabilities are common in both high-income as well as low-income countries. UNICEF estimated that the number of children with disabilities below the age of 18 years was about 150 million. In low-income countries, the prevalence of childhood disability ranged between 0.4 and 12.7%. According to Census 2001, the prevalence of childhood disability in South Africa was between 2-3 %. It is commonly accepted in the literature that the aetiology of childhood disability is attributed to prenatal, perinatal and postnatal factors. However, disabilities within the African context have been associated with beliefs and spirituality retribution such as the "*will of God* or *witchcraft*". The purpose of the study is to establish what the caregivers attribute as the cause of childhood disabilities in the rural community of South Africa. A qualitative, exploratory and descriptive approach was used to obtain the participants' perspectives on the cause of childhood disability. Data were collected from caregivers of children with disabilities using individual face-to-face interviews (n=9) and three focus group discussions (n=10) at Nkhensani Hospital in Giyani, Limpopo Province, South Africa. Caregivers perceived "*religious beliefs, other beliefs, biomedical factors* and *lifestyle and habits* as possible causes of childhood disabilities. Even though belief-based-factors cannot be scientifically proven as potential causes of childhood disability, health care professionals should ensure at all times that they take into consideration the clients' culture and beliefs during assessment and or treatment of the child.

Keywords: Childhood disability, cause of disability, caregiver, and rural community.

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Introduction

Childhood disabilities are conditions that affect or are likely to influence the development of children into adulthood. The conditions may have a neurological basis, musculoskeletal components, genetic syndromes and cognitive, behavioural and communication disorders (Rosenbaum & Gorter, 2012). Children with disabilities (CWDs) refer to persons below the age of 18 who have a physical, mental, intellectual and sensory impairment that may hinder their full and effective participation in society on an equal basis with other children

(WHO, 2007). CWDs have health conditions such as cerebral palsy, hydrocephalus, developmental delay, achondroplasia, spina bifida and Down syndrome.

According to the World Report on Disability, childhood disability is a phenomenon found in both low-middle-income countries (LMIC), as well as high-income countries (HIC) (WHO, 2011). The prevalence of CWDs in the world is not known (WHO, 2011). However, the Global Burden of Disease commissioned in 2004 estimated that the number of children between the ages of 0 to 14 years living with moderate to severe disabilities is about 93 million, which is 5.1 % of the global population (WHO, 2008). UNICEF estimated that the number of CWDs below the age of 18 years is about 150 million (UNICEF, 2005). A review of the literature in LMIC indicated that the prevalence of childhood disability ranged between 0.4 and 12.7 % (Maulik & Darmstadt, 2007). Two studies conducted in Ghana and South Africa suggested that the prevalence of childhood disability is at 1.8 and 6 % respectively (Biritwum, Devres, Ofosu-Amaah, Marfo & Essah, 2001; Couper, 2002). According to Census 2001, the prevalence of childhood disability in South Africa is 2.1 % for children aged 0- 9 years and 3 % for children aged 10- 17 years (STATSSA, 2005:12).

It is commonly accepted amongst researchers in paediatrics that the aetiology of childhood disability is attributed to prenatal, perinatal and postnatal factors (Gladstone, 2010; Maimburg, Bech, Vaeth, Møller-Madsen & Olsen, 2010; Jauhari, Boggula, Bhave, Bhargava, Singh, Kohli, Yadav & Kumar, 2011).

In LMIC poverty, poor health, and poor nutrition of pregnant or lactating mothers as well as infants and young children are also thought to increase the risk of childhood disabilities (Grantham-McGregor, Cheung & Cueto, 2007). However, caregivers of CWDs often have varying perceptions of the potential causes of children's disabilities. A study of Pakistani families in the UK reported that caregiver's perceived causes of children's disabilities were religious in origin. These caregivers believed that: (1) the child was a gift from God, (2) the child was a test from God, (3) the parents of the CWD were chosen, and (4) the parents of the CWD were being punished or even cursed (Croot, Grant, Cooper & Mathers, 2008). In addition, other Pakistani families' associated biomedical reasons and their individual behaviours such as the types of food they consumed to be some of the possible causes of childhood disabilities.

Disabilities within the African context such as South Africa, Tanzania, Ethiopia, Uganda, and Tanzania have been associated with beliefs and spirituality or divine retribution such as the "will of God or witchcraft" (Mckenzie, McConkey & Adnams, 2013). Studies by Kisanji (1998) and Mulatu (1999) have suggested that age and educational level of a person are likely to influence whether beliefs

or spiritual factors are seen as a cause of disability within some African countries. These authors believe that the younger and highly educated Africans are less likely to attribute beliefs and spirituality to be a cause of disabilities. Therefore, the purpose of this study was to establish what caregivers attribute as the cause of children's disabilities in the rural community of Giyani in Limpopo Province, South Africa.

Methodology

Design of the study

A qualitative, exploratory and descriptive approach was used to obtain the participants' perspectives on the cause of childhood disability. Qualitative research is used to collect data in a face-to-face situation by interacting with caregivers of CWDs with the aim of understanding the participants' meaning from their own perspectives of the causes of childhood disability (McMillan & Schumacher, 2006). An exploratory and descriptive approach was used to examine the *"little-understood"* phenomena of the causes of childhood disabilities from an African perspective (Babbie & Mouton, 2001; McMillan & Schumacher, 2006). Data were collected using individual face-to-face interviews and focus group discussions (FGDs) with caregivers of CWDs, who had been attending the rehabilitation clinic at Nkhensani Hospital in Giyani.

Study setting

The study was conducted at Nkhensani Hospital in the township of Giyani in the Limpopo Province of South Africa. Giyani is a rural area consisting of 10 traditional authorities, 91 villages and a town with a population of about 244 217 people (STATSSA, 2012).

Participants

The sampling of caregivers of CWDs was informed by a large estimated number of caregivers attending the rehabilitation clinic at Nkhensani Hospital as reported by the rehabilitation professionals. Caregivers were sampled with the aim of achieving redundancy of data. Rehabilitation professionals assisted the researcher in identifying caregivers who: (1) had a CWD aged 0-15 years, (2) attended at least three rehabilitation sessions at the clinic (3) were over the age of 18. Caregivers who participated in the face-to-face interviews were excluded from participating in the FGDs.

A total of nine (*n=9*) caregivers were recruited for the face-to-face interviews. A total of three groups, comprising two (*n=2*), three (*n=3*) and five (*n=5*) caregivers were respectively recruited to participate in the FGDs. The

demographic characteristics of caregivers who participated in the interviews and FGDs are presented in Tables 1 and 2, respectively.

Table 1: Demographic characteristics of caregivers- face to face interviews

Code	Age	Gender	Relation to child	Educational level	Employment status	Child's diagnosis
CG1	29	Female	Mother	Grade 8	Unemployed	Cerebral palsy
CG2	28	Female	Mother	Grade 8	Unemployed	Cerebral palsy
CG3	38	Female	Mother	Grade 11	Unemployed	Cerebral palsy
CG4	33	Female	Mother	Grade 11	Unemployed	Achondroplasia
CG5	18	Female	Mother	Grade 11	Unemployed	Microcephalus
CG6	29	Female	Mother	Grade 10	Unemployed	Cerebral palsy
CG7	29	Female	Mother	Grade 11	Unemployed	Cerebral palsy
CG8	23	Female	Mother	Grade 10	Unemployed	Cerebral palsy
CG9	23	Female	Mother	Grade 11	Unemployed	Cerebral palsy

Table 2: Demographic characteristics of caregivers- focus group discussions

Group	Code	Age	Gender	Relation to child	Educational level	Employment status	Child's diagnosis
1	R1	49	Female	Mother	Grade 7	Unemployed	Down syndrome
	R2	23	Female	Mother	Grade 10	Unemployed	Cerebral palsy
2	R3	20	Female	Mother	Grade 12	Unemployed	Cerebral palsy + epilepsy
	R4	34	Female	Mother	Grade 12	Unemployed	Cerebral palsy
	R5	24	Female	Mother	Grade 11	Unemployed	Cerebral palsy
3	R6	43	Female	Mother	Grade 11	Unemployed	Microcephalus
	R7	53	Female	Grandmother	No formal education	Unemployed	Cerebral palsy
	R8	18	Female	Mother	Grade 10	Unemployed	Cerebral palsy
	R9	28	Female	Mother	Grade 11	Unemployed	Cerebral palsy
	R10	26	Female	Mother	Grade 11	Unemployed	Cerebral palsy

Procedure

All participants in the study, were asked the same question- "*what can you tell me about this child*?" The question elicited participants' responses on how the child was born as well as what they perceived to be the cause of the child's disability.

Interviews with caregivers

Semi-structured face-to-face interviews with guiding question were used to interview caregivers. Semi-structured interviews in qualitative studies elicit participants' unlimited response and as such, pilot testing was deemed unnecessary (McMillan & Schumacher, 2006: 204). The researcher conducted all the interviews and coordinated the conversations with the aim to generate data (Birks & Mills, 2011:75). All interviews were carried out in Xitsonga language and recorded using two digital audio recorders. Probing was used to stimulate caregivers to elaborate on what they said.

Focus group discussions with caregivers

A total of three FGDs were conducted at Nkhensani Hospital on three different dates. The first group had two participants; the second had three, and the third had five participants. The researcher facilitated all FGDs in Xitsonga language, but some of the participants responded in Sepedi Language.

Analysis

Data generated from the interviews and FGDs were transcribed verbatim by two senior university students who were trained by the primary researcher/ first author to be data transcribers. Verbatim transcripts were verified and corrected by the first author who later translated them into English. All transcripts were uploaded into a qualitative data analysis programme (*Atlas.ti v6*). *Atlas.ti* was only used to store and organise data; the first author manually coded all data using conventional content analysis approach (Hsieh & Shannon, 2005). The conventional content analysis is similar to an inductive approach to qualitative data analysis in the sense that they are not associated with any individual qualitative approach but generic in nature and may be applied to different types of research methods (Ezzy, 2002; Silverman, 2000).

Data were read word by word, line by line to generate codes. In-vivo codes, which are codes generated from participants' own words were used (Muhr, 2004; Saldana, 2013). Similar and related codes were grouped together into categories. Related categories were grouped into themes.

Strategies to ensure trustworthiness

Trustworthiness refers to the activities that were implemented to ensure that qualitative data were gathered and analysed rigorously to ensure that the outcome of the research is correct (Speziale & Carpenter, 2007). Credibility, dependability, confirmability, and transferability are the four criteria used to demonstrate trustworthiness of qualitative research (Lincoln & Guba, 1985). Measures were taken to ensure *credibility* such as (1) the utilization of a recognised research method, (2) the use of different data collection strategies, (3) debriefing sessions between the first author of the article and the supervisor, (4) detailed description of the procedure followed, and (5) comparing the findings of the study with existing literature (Shenton, 2004). In addition, the researcher had knowledge of the local language and culture and had been a resident of Giyani for over 10 years.

Even though the aim of the current study was not to generalise the findings, the detailed presentation of the methodology and the demographic characteristic of the participants will ensure that the findings will have meaning or *transferability*

to participants in a similar situation who have the same demographic characteristic with participants of the current study (Speziale & Carpenter, 2007). The detailed methodological presentation and demographic characteristic of the participants will not only ensure *transferability* but *dependability and confirmability*. *Dependability* is the extent to which the findings of two studies would be similar if the same methodological procedures were followed (Shenton, 2004). *Confirmability* is the degree to which researcher's bias are eliminated by detailing how the research was conducted and analysed.

Ethical consideration

The study was approved by the Ethics Committee of the University of Pretoria (Protocol 109/2009) and the Limpopo Department of Health. All participants in the study signed an informed consent form.

Results

Caregivers in this study have expressed what they perceived to be the cause of childhood disability. Four major themes emerged from analysis of data: (1) *Religious belief*, (2) *Other belief*, (3) *Biomedical factors, and* (4) *Lifestyle and habits.*

Theme 1: Religious belief

Caregivers thought that one of the causes of childhood disability were based on *religious belief*. Theme 1 (*religious belief*) is made up of three categories (*witchcraft, God's decision* and *curse*) and eight codes. As illustrated in Table 3, there are participants who thought that their children were disabled due to the acts of *witchcraft*. Some participants felt that their children were disabled because it was *God's decision*. These caregivers expressed that a CWDs was a gift from God. However, there is a participant who thought that the child was disabled due to a *curse* that she had as a mother.

Table 3: Theme 1- religious belief

Theme	Category	Code	Excerpts
Religious belief	Witchcraft	Bewitched	*…maybe she has been bewitched. (CG 4)*
		People are responsible	*...there are people who are responsible for causing the disability. (Group 1: R2)*
	God's decision	I thank God for everything	*...my child's condition is not my fault. I thank God for everything…(CG 1)*

Theme	Category	Code	Excerpts
		Gift from God	*…when God gives you something you just have to accept because you did not choose…(CG 8)*
		It is from God	*It is from God, and I cannot say another human being has caused it. It is from God…I do not have a problem with having a child with disabilities I have accepted it as a gift from God. (Group 1: R1)*
		God's will	*…there are those that accept that it is God's will.(CG 9)*
		It was caused by God.	*…it was caused by God...(Group 1: R2)*
	Curse	Cursed	*…maybe I have been cursed. (Group 1: R1)*

Theme 2: Other belief

Participants were also of the view that some of the causes of childhood disability were based on *other belief*. Theme 2 (*other belief*) as shown in Table 4 is made up of a single category (*misconception*) and four codes. There are caregivers who believed that childhood disability was a direct result of the child having holes in the brain, or the foetus defecating/relieving herself in the womb or the lack of stepping relax immediately after birth.

Table 4: Theme 2- other belief

Theme	Category	Code	Excerpts
Other belief	Misconception	Her brain was all over the place	*…I was told that her brain was all over the place, and she had holes in her brain…(CG 5)*
		Had holes in her brain	
		Baby had relieved herself	*…it seemed as if the baby had relieved herself while still inside the womb as the water that broke was green (CG 7)*
		Lack of stepping reflex	*It happens when a child is born without being able to stand on their feet [stepping reflex]…(Group 3: R4)*

Theme 3: Biomedical factors

Some of the participants in the study have suggested that childhood disability was caused by *biomedical factors*. Theme 3 (*biological factors*) emerged from

four categories (*head injury, hypoxia, poor immunization* and *stress in pregnancy*) and five code. Caregivers have suggested that head injury, oxygen deprivation, defaulting of the child's immunization and the mother's stress in pregnancy could be possible factors responsible for childhood disability as illustrated in Table 5.

Table 5: Theme 3- biomedical factors

Theme	Category	Code	Excerpts
Biomedical factors	Head injury	Head injuries	*…the midwife thought she had some head injuries (CG 4)*
	Hypoxia	Oxygen deprived	*…they then said the child is oxygen deprived…(CG 7)* *…she was put on oxygen for some time after birth. So they though the oxygen could have caused some damages. (Group 2: R3)*
	Poor immunisation	Default on immunization	*….it is caused by defaulting on the immunisation programme. (Group 3: R5)*
	Stress in pregnancy	Stress Thinking a lot	*They said stress caused this. I was thinking a lot while pregnant. (Group 2: R2)* *It is caused by the mothers who think a lot during pregnancy.(Group 3: R2)*

Theme 4: Lifestyle and habits

Some participants were of the view that *lifestyle and habits* of the pregnant mother could be a possible cause of childhood disability. Theme 4 (*lifestyle and habits*) is made of two categories (*smoking and drinking* and *spicy food*) and four codes. The caregivers have suggested that drinking of alcohol, smoking of tobacco and consumption of spicy foods during pregnancy could result in disability to the newly born child as depicted in Table 6.

Table 6: Theme 4- lifestyle and habits

Theme	**Category**	**Code**	**Excerpts**
Lifestyle and habits	Smoking & drinking	Drinking Smoking	*Yes, you will find that some mothers drink or smoke while they are pregnant. (Group 3: R3)*
	Spicy food	Atchar Chilly food	*…I think the child got this from the mother as a result of the food that the mother used to eat…she used to eat atchar and a lot of chilly foods during pregnancy. (Group 3: R5)*

Discussion

The development of concept on the cause of childhood disability was based on the perspectives of caregivers during the face-to-face interviews and FGDs. Caregivers' perspectives on the cause of their children's disabilities were based on (1) their *religious beliefs*, (2) their o*ther beliefs*, (3) *biomedical factors*, and (4) their *lifestyle and habits*.

Religious and other beliefs

Caregivers in the present study thought that their religious beliefs and other beliefs are a possible cause of childhood disabilities. This finding as reported in the current study is similar to what was found in other studies. According to Hebert and Koulouglioti (2010), caregivers of CWDs have different beliefs about the possible cause of their children's disabilities such as genetic factors, events surrounding the child's birth, and environmental influences in the early childhood period. In addition, some caregivers attribute their children's disability to immunisations. Two studies have found that caregivers of CWDs think that theological- or religious-based beliefs are responsible for causing childhood disabilities (Croot *et al.,* 2008; Daudji, Eby, Foo, Ladak, Sinclair, Laundry, Moody & Gibson, 2011).

Some of the caregivers who participated in the current study believed that the lack of a child's stepping reflex or not crying directly after birth was also responsible for causing childhood disability. This belief is a misconception because the lack of a stepping reflex or not crying at birth that is associated with low Apgar score may be an indication or sign that the child may have a neurological or developmental problem (Lie, Grøholt & Eskild, 2010).

The implication of religious and other belief-based causes of childhood disability is that pregnant and expecting mothers need to be educated about factors that could endanger the lives of their unborn babies as well those factors that could result in disability.

Biomedical reasons

In modern medicine, belief-based reasons are not considered to be a possible cause of childhood disabilities as there is no evidence to support it. Instead, biomedical reasons are deemed to be the primary cause of childhood disabilities (Jauhari *et al.,* 2011; Karthikeyan & Ramalingam, 2012; Mcintyre, Taitz, Keogh, Goldsmith, Badawi & Blair, 2013). Several studies have suggested that infectious diseases are a leading cause of childhood disability (Kristina, Kate, Gudrun, Marian, Teresa, Ulla-Britt & Bo, 2013; Khandaker, Muhit, Rashid, Khan, Islam, Jones & Booy, 2014). The infectious diseases that have a potential

to cause childhood disabilities include amongst others congenital rubella syndrome, pneumococcal, meningococcal and *Haemophilus influenza* type b meningitis are all preventable by using vaccines (Maulik & Darmstadt, 2007). The lack of vaccination or immunisation was also suggested by caregivers who participated in the face-to-face interviews and FGDs as a possible cause of disability. To reduce the likelihood of disability due to preventable infectious disease, Ibrahim and Bhutta (2013) has highly recommended that children should be immunised.

As alluded to by the caregivers who participated in the present study, hypoxia has been reported in the literature as a possible cause of disabilities in children (Nielsen, Schendel, Grove, Hvidtjørn, Jacobsson, Josiassen, Vestergaard, Uldall & Thorsen, 2008; Fatemi & Folsom, 2009; Natarajan, Shankaran, Pappas, Bann, Tyson, McDonald, Das, Hintz, Vohr & Higgins, 2014). However, a review of the literature by Ellenberg and Nelson (2013) has suggested that the currently available data does not support the belief that birth asphyxia can be recognised as an actual cause of disability.

Some caregivers in the present study have reported that head injury to the child during birth is a possible cause of disability. These caregivers' suggestions may be considered to be true considering that there is sufficient evidence in the literature to support the idea that head injuries are responsible for causing childhood disabilities. According to Bax, Flodmark, and Tydeman (2007), an insult or injury to the brain before birth or in early childhood may result in childhood disability.

Stress during pregnancy, as suggested by some caregivers who participated in the present study, is also likely to cause childhood disabilities. According to Loomans, Van Dijk, Vrijkotte, Van Eijsden, Stronks, Gemke and Van Den Bergh (2013) pregnant mothers who experience psychosocial stress are at risk of delivering babies with an adverse birth outcome such as disability. According to Schetter and Tanner (2012) anxiety, depression, and stress in pregnancy are risk factors for adverse outcomes for mothers and children. Anxiety in pregnancy is associated with shorter gestation and has negative implications for foetal neurodevelopment and the child outcomes (Schetter & Tanner, 2012).

Lifestyle and habits

The idea that a pregnant woman's lifestyle and habits may result in disability of the unborn child has also been reported in other studies. Croot *et al.* (2008) have suggested that the use of alcohol and tobacco in pregnancy can result in some degree of developmental delay or disability in the child. According to Peadon, Payne, Henley, D'Antoine, Bartu, O'Leary, Bower and Elliott (2011) alcohol is teratogenic/harmful, and drinking during pregnancy may lead to growth

restriction, birth defects, and structural and or functional problems of the central nervous system in the exposed foetus. A study conducted in Denmark has shown a significant association between heavy maternal smoking (> 10 cigarettes per day) during pregnancy and risk of childhood disability, but no significant association was found for moderate smoking (Streja, Miller, Bech, Greene, Pedersen, Yeargin-Allsopp, Braun, Schendel, Christensen, Uldall & Olsen, 2013).

Some caregivers in the current study indicated that consumption of what the perceived as "bad" food during pregnancy such as spicy food may be responsible for causing childhood disabilities. However, Gao *et al.* (2013) suggested that avoidance of certain foods during pregnancy is associated with mother's cultural beliefs and does not necessarily mean that there would be an adverse impact on the child. Instead, *Capsicum annuum L,* which is a chemical found in pepper contains vitamin A and C as well as having antioxidant properties which are suitable for both the pregnant mother and the child (Mateos, Jiménez, Román, Romojaro, Bacarizo, Leterrier, Gómez, Sevilla, del Río, Corpas & Palma, 2013). This example indicates how important it is for pregnant mothers to receive an appropriate nutritional education.

Limitations

The study had several limitations such as the small sample sizes in the face-to-face interview participants as well as the FGD groups. Secondly, the demographic characteristics of the participants were similar regarding age, gender, relationships with the child, educational level, employment status and the diagnosis of children. As such, the finding of this study cannot be generalised to the general public but can only be applied to other situations matching the demographic characteristics of the participants in this study.

Conclusion

The current study reported on the causes of childhood disability as perceived by the caregivers of CWDs in the rural community of Giyani in Limpopo Province, South Africa. The findings of the study have shown that the causes of childhood disability were centred around four themes; (1) *Religious belief*, (2) *Other belief*, (3) *Biomedical factors, and* (4) *Lifestyle and habits. Religious belief, other belief,* and part of the *lifestyle and habits* (under the category of spicy food) have no scientific basis, meaning that they are not supported by existing literature. On the other hand, *biomedical factors* and part of *lifestyle and habits* (under the category of smoking and drinking) had a scientific basis and supported by the existing literature. The implication of the finding of the current study is that health care professionals should ensure at all times that they take into consideration the clients' culture and beliefs when assessing and treating

pregnant and expecting mothers as well as when evaluating and or treating babies or a child.

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