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SOCIOLOGY | RESEARCH ARTICLE

Perceptions and treatment of children with cerebral palsy among the Tonga of Binga in Zimbabwe

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Abstract: *Background:* While disability is universal, there is a marked variation in caregivers' experiences of caring for children with disabilities. Therefore the diversity of disability experiences across the world needs to be acknowledged in order to understand care practices relative to disability. *Aim:* The paper explores the link between disability perceptions and treatment among the Tonga of Binga through their disabled children. *Method:* A total of 53 participants were enrolled in a longitudinal, qualitative and ethnographic study. Data was collected through in-depth interviews, participant observation and focus group discussions. The primary researcher returned to the field over time to explore changes and the processes associated with these changes from 2005 to 2013. *Data analysis:* Thematic analysis was conducted to discern recurring patterns within the data. *Results:* The results showed both positive and negative attitudes and behaviour towards children with disabilities; and the complexities of these influenced by their historical background, life experiences, social, cultural and economic factors. *Policy consideration:* Local cultural knowledge for policy designing and implementation.

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PUBLIC INTEREST STATEMENT

The diversity of disability experiences across the world needs to be acknowledged in order to understand care practices relative to disability especially in the developing world where there is scarce information due to lack of research. The researchers studied the Tonga of Binga in Zimbabwe. They are marginalised, vulnerable and chronically poor communities whose life experiences in the field of disability are still not understood and therefore need to be researched and documented. As a result, the researchers studied families of disabled children through a longitudinal, ethnographic qualitative study (2005–2013) of children with cerebral palsy from birth to early teenage hood. Disability attitudes, perceptions, beliefs and treatment of disabled children were noted. It was observed that the Tonga displayed both positive and negative attitudes and behaviour towards disability; influenced by their history, life experiences, social, cultural and economic factors. This information is therefore important for academics, professionals carrying out work among these communities, non-governmental organisations as well as government policy and implementation.

Subjects: Anthropology - Soc Sci; Sociology & Social Policy; Sociology of Culture; Disability Studies - Sociology

Keywords: disability; attitudes; beliefs; culture; caregivers; disabled children

1. Introduction

This paper highlights Tonga caregivers' beliefs, perceptions and care of disabled children. There is a scarcity of literature concerning disability in poor contexts generally and among the Tonga ethnic groups of Zimbabwe specifically. Examination of attitudes towards people with disabilities across cultures suggests that societal perceptions and treatment of persons with disabilities are neither homogeneous nor static (Amoako, 1977; Roeher, 1969). Caregivers' perceptions and treatment of disabled children varies significantly from one context to another, with societal attitudes and perceptions playing a significant role in determining the extent to which a disabled child will be cared for (Curran & Runswick-Cole, 2013; Goodley, 2011). Furthermore most people gave their own specific understanding of the cause and development of a disease that draws partly on the repertoire of general beliefs but also on situational factors of social, economic and political nature (Abberly, 1987; Goodley, 2011; Talle, 1995). Thus, cultural and contextual factors that influence caregivers' perceptions towards disability need to be documented and explored for their contribution to cross-cultural knowledge about disability.

2. Background

Disability has been described as a complex, dynamic and multidimensional concept (Shakespeare, 2014; World Health Organisation, 2011), subject to many definitions from different perspectives and used for different purposes in disciplines ranging from medicine, sociology to political sciences (Mitra, 2006). In all societies, there are beliefs about sickness, health and disability with different societies having different explanations on causes of disability, beliefs and attitudes, perceptions and behaviour towards disability (Munsaka, 2012; Talle, 1995; World Health Organisation, 2011). Talle (1995) and Trescher (2017) argue that in order to understand the concept of disability one needs to look at cultural beliefs as well as a contextual analysis in order to grasp the phenomenon in its full social and cultural setting. People with disabilities have been labelled socially excluded, marginalised, vulnerable and chronically poor (Elwan, 1999; Khupe, 2010; Lang & Charowa, 2007; Lwanga-Ntale, 2003; Muderedzi, Eide, Braathen, & Stray-Pedersen, 2017; Sen, 1999; Yeo, 2005). In most traditional African cultures, including Zimbabwe, there is a strong belief that people's lives are controlled by ancestral spirits and that disability is of spiritual origin (Marongwe & Mate, 2007; Mpofu & Harley, 2002; Shoko, 2007). Disability stigma (discrimination) as well as curtesy stigma (discrimination acquired as a result of being related to a person with a stigma) has been noted to be present in Zimbabwe (Khupe, 2010; Lang & Charowa, 2007).

Historically, there has been a number of different definitions and understandings of disability, such as supernatural, spiritual and religious (Braathen, Munthali, & Grut, 2015; Goodley, 2011; Munsaka, 2012) with disability generally equated with incapability (World Health Organisation, 2011) and persons with disability as a burden to society (Khupe, 2010; Lang & Charowa, 2007). One widely documented conceptualisation of disability in African contexts is that a child born with a disability is seen as a curse, and should be hidden. One reason given for the curse is that the mother is punished for wrongdoing, and the child is living proof of her error (Curran & Runswick-Cole, 2013; Gona, Mung'ala-Odera, Newton, & Hartley, 2011; Marongwe & Mate, 2007; UNESCO, 2001). On the other hand, studies from African communities such as the Xhosa in South Africa (Mckenzie & Swartz, 2011), BaTswana in Botswana (Ingstad, 1997), and Maasai in Kenya (Talle, 1995) have found that children born with anomalies were seen as "a gift from God" and remained valued members of the community. In Zimbabwe, Dengu (1977) found that it was through the introduction of Christianity that disabled children started to be seen as gifts from God, although in some cases feelings of shame persisted, leading to cases of hiding.

Perceptions and beliefs about disability as a punishment, the result of ancestral anger or retribution by divine forces, have been found in many cultures (Braathen & Ingstad, 2006; Coleridge, 1993; Devlieger, 2005; Talle, 1995). A study from Ghana, (Wright, 1960) found that children with disabilities were seen as protected by supernatural forces, were the reincarnation of a deity and were always treated with kindness, gentleness and patience. Studies among the Shona and Kalanga of Zimbabwe, (Khupe, 2010; Lang & Charowa, 2007) have highlighted negative attitudes such as disabled people constitute a burden to society and that disability is associated with evil. A study by Jackson and Mupedziswa (1988) among the Karanga in Zimbabwe found that beliefs and attitudes expressed by informants toward persons with disability often seemed to be in contradiction with how they acted towards them.

It is important to note that while in Western societies impairment is primarily seen as an individual affair and functionally limiting at the bodily or cognitive level, in many non-Western societies what is perceived to be the cause and/or consequences of impairment may be dysfunctional social relations or the transgressing of social order (Shuttleworth & Kasnitz, 2005). Despite the emergence of the social model and the rights approach to disability, culture and religion still influence the understanding of disability substantially in many societies (Reinders, 2011; Trescher, 2017).

Attitudes and perceptions are socially as well as culturally constructed and dynamic in nature and may vary with the social situation in which they are acted upon (Edgerton, 1970; Ingstad, 1997). Ingstad and Sommerschild (1983) found that previous life experiences are another important source of influence on people's attitudes and behaviour toward disabled persons. They found that previous positive experiences in handling other types of crises became a source from which parents could draw when they got a disabled child. They identified two types of reactions to the experience of having a disabled child; those who said that they got a terrible shock which it took them sometime to overcome, and those who saw it as just one of those things that happen in life. Differences in attitudes towards a disability depended on whether or not it is perceived as a troubling disability in that it causes problems for others and takes the mother away from carrying out chores necessary for the survival and daily life of the family. Each family would have their own constructed notions of disability that might influence the treatment of and relationship with the disabled child (Ingstad, 1995).

2.1. Study context – Binga district

The Tonga are a small ethnic minority found in Binga district in Matabeleland North Province on Zimbabwe's north—western border with Zambia. They are descendants of “the river Tonga”, evicted from the Zambezi valley in 1957 to make way for the Kariba dam (McGregor, 2009). They had to escape into the arid, higher regions on both sides of the Zambezi valley, where agriculture is almost impossible resulting in perennial famines and high infant mortality due to hunger and lack of health care. The dam brought hydro-electric power and wealth to the country but bypassed the Tonga (Basilwizi Trust, 2004; Mashingaidze, 2013; McGregor, 2009). The river Tonga still express a deep sense of loss at leaving behind the shrines (*malende*), sacred caves, pools and graves of their ancestors. They claim the lake destroyed their ancestral burial grounds and effectively disrupted their way of life (Muntanga, 2001).

Binga district is dominated by Tonga culture and characterized by political oppression and isolation (Basilwizi Trust, 2004; McGregor, 2009; Munsaka, 2012). Despite the effects of globalization in Zimbabwe, Tonga cultural beliefs still dominate understanding about the causes and implications of bodily impairment (Munsaka, 2012). Having lost almost everything, Tonga culture has survived, and is a strong driving force for self-assertion, resilience and development. They still turn to this for answers to experiences of misfortune, such as disease, disability and death (Muderedzi et al., 2017; Munsaka, 2012; Muntanga, 2001).

The settling of European missionaries in most parts of the country resulted in the conversion of large parts of the population to Christianity. However, missionaries did not settle in the Zambezi valley due to harsh weather conditions such as extreme temperatures, little rainfall and malaria

(Colson, 1970; Tremmel & the River Tonga People, 1994). This has resulted in the Tonga relying on their cultural beliefs without much outside influence (Siamwiza, 2013). The matrilineal lineage and clan, along with polygynous marriage systems are seen as assets that facilitate broad social networks and flexible systems of resource access, helping people meet material needs (Siamwiza, 2013). Binga district is situated in a province that has the highest poverty rate in the country with 70% of its inhabitants classified as poor or extremely poor (Basilwizi Trust, 2004; Rural Poverty in Zimbabwe; Rural Poverty Portal, 2015; Zimbabwe National Statistics Agency [ZIMSTAT], 2012). Unlike other parts of the country that are well developed, Binga district's lack of healthcare access is well documented (Muderedzi, 2006; Tremmel & the River Tonga People, 1994). Issues such as financial constraints, lack of healthcare centres leading to long distances for access, lack of road infrastructure resulting in lack of public transport, lack of medications, lack of human resources such as trained staff and wild animal attacks in remote areas results in healthcare inaccessibility. There are no government disability grants or assistive devices for disabled children and no economic support for the parents since the economic meltdown in the late 1990's.

Model for Coping with Disability (Ingstad & Sommerschild, 1983) was used to develop the study due to its inclusiveness of family experiences of living with both disabled and non-disabled children since the model encompasses two perspectives; the diacronic (time) perspective that portrays coping with a disabled child as a process; and the synchronic (system theoretical) perspective that sees the child as part of a larger whole (family, community and society). The model gives a description of the observable social forms as well as understanding and explaining the social processes that generate them; inclusive of its cultural dimension comprising of variables such as ethno-medical beliefs, past and present life experiences and attitudes towards disability. The diacronic perspective enabled the longitudinal perspective of the study through follow-up visits to the families.

2.2. Materials and methods

The data presented in this article were collected as part of a larger qualitative longitudinal research project on coping behaviours of Tonga families of children with disabilities in Binga district in Zimbabwe (2005–2013). The study also included a retrospective aspect (looking back in time) to explore how earlier experiences influence present views and behaviour. The study was longitudinal, qualitative and ethnographic in nature (Sandelowski & Barroso, 2003; Silverman, 2013). The primary researcher (corresponding author) returned to explore changes which occurred over time and the processes associated with these changes (Farrall, 2006). The longitudinal aspect was secured through repeated observations of children with cerebral palsy over long periods of time and how families coped with disability problems from birth through to childhood and early adolescence.

Caregivers from 53 families with children with disabilities were selected purposively based on characteristics highlighted in the theoretically developed research questions (Silverman, 2013). Informants were selected to represent Tonga caregivers of children with cerebral palsy in age groups (birth–5 years and 8–13 years). The caregivers consisted of 35 parents, 15 extended families and 3 child headed families (12–15 years of age) with adult relatives in the same homesteads. The first cohort (2005) consisted of caregivers of 30 children (birth–5 years of age) of which 23 of the children died during the first two years of the study (from malaria, diarrhea, meningitis and other infections). The second cohort (2012) consisted of 7 from the first cohort and 23 new recruits (8–13 years old). Cerebral palsy was chosen to represent a multitude of impairments including muscle weakness, stiffness, clumsiness, emotional and developmental problems; and due to its apparent high prevalence in the area, as reported by local community health workers.

To improve the likelihood of accuracy and objectivity, the project used a triangulation of qualitative methods: 53 in-depth interviews; participant observations with 20 families, 10 focus group discussions; as well as field notes and secondary data (documents). All the activities were conducted in the local language chiTonga. The aim was to encourage informants to speak personally and at length about their lives as caregivers bringing out their disability beliefs, attitudes and treatment of disabled children and youth.

In-depth interviews were conducted using open-ended questions to allow individual variation (Patton, 1990). The primary researcher and the research assistant carried out interviews at the homesteads of the informants. The interviews lasted for an hour or more. The interviews were tape recorded, transcribed verbatim and translated to English.

Participant observation was chosen as a process of enculturation (Schensul, Schensul, & LeCompte, 1999), where the researcher absorbs the big picture and some details leading to an understanding of people's daily lives, structure and events, social structure, expectations and values. It also allows for the juxtaposition of what people say they do and what they are observed to do. Twenty families (10 in each cohort) volunteered to host the researchers for a stay of 3 days at each homestead. The primary researcher (a Zimbabwean, but not from Binga District) and the research assistant (a Tonga from the district) were immersed in most activities of daily living, such as fetching water and wild fruits; looking after the disabled child; attending community gatherings, so as to gain more depth and insight into informants lives. This also allowed the researchers to meet the extended family and neighbours especially in the evenings where disability songs, stories, and life in the Zambezi valley were narrated.

Two hour long focus group discussions were conducted in groups of 8 inclusive of both genders at their chosen central place such as a school or clinic and tape recorded. The same general questions on disability issues were discussed in all the groups. The groups assisted informants to further explore and clarify their points of view. Five group discussions were carried out with each cohort. The interviews consisted of questions regarding their understanding of disability, the child's cause of disability, and reactions on realising the child's disability; coping with disability, community perceptions and the future of the disabled child.

Ethical approval was obtained from the Medical Research Council of Zimbabwe (MRCZ/286) and the Eastern Regional Medical Ethics Committee (REC-case 2015/397) in Norway. Purposive sampling inclusive of snowball sampling was used to identify the 53 informants who were recruited at their homesteads in all the wards. The aim of the study was explained to the informants who gave their consent by signing a consent form or putting an "X" figure as signature.

2.3. Data analysis

Data analysis was an ongoing process from the start of the data collection using content analysis. Data were labelled through open coding, using conceptual categories to develop the codes (Silverman, 2013). The codes were derived both from the literature and the actual data (Corbin & Strauss, 2008). The coded data was read several times and four factors were identified: (1) Tonga historical/present meaning of disability; (2) perceived causes of disability; (3) reactions to disability; (4) beliefs and attitudes.

3. Results

3.1. Historical/present meaning of disability

Retrospective information on disability was gathered from the "river Tonga" (men and women 80 years and above—evicted from the valley in their 20s) through formal and informal interviewing that took place at the homesteads during in-depth interviews and participant observation. They narrated their history from the time when they were living in the valley to date. An oldman in his 80s stated;

We were told by our forefathers that children with disabilities were killed back then in the valley. We never witnessed it as young men and women in the valley for it had been stopped by then. Since then we never heard of anyone doing it. Historically infanticide took place with twins, a child cutting the upper teeth first, born with a cord round the neck, born feet first as well as visible anomalies. Our forefathers believed that such children brought bad luck or curse to the community. Curses were in the form of breakouts of diseases, locusts

or birds devouring our harvests or other misfortunes. The poor children were left to die in large anthills in the forest and the elderly women would encourage the grieving mother to have another baby as soon as possible. We are told that infanticide was stopped due to high infant mortality as a result of diseases such as malaria, measles and other infections which would wipe out some families' children. As a result of this, disabled children as well as the rest mentioned were no longer killed but taken care of as well as the rest of the children. It was better for a family to have a disabled child than no child.

When asked to define disability, both genders young and old made statements such as;

“I do not understand”—“An illness caused by being bewitched (*kuchiswa*)”—“Someone who cannot do anything for him/herself”—“someone who cannot work and their future is not certain”—“It is caused by ancestors' sorrow”—“Disability is when one is not able to help themselves. I knew of someone who was disabled, led a miserable life for he could not help himself most of the time. People used to help when they could but it was his family that helped him all the time”.

When asked to state the meaning of disability, the informants, the extended family as well as the community explained that it is one of those things that happen in life, as if trivializing the phenomenon, with some shrugging their shoulders or showing open palms.

Many stated that when having a child they were mainly worried about whether or not the child would survive; and not the presence of a visible disability. Bodily imperfections were seen as important only to the extent that they impaired normal functioning in society; otherwise disability was perceived as part of life and therefore they believed that disabled children should be taken care of. For example, a deaf child managing to herd goats with other boys was referred to as managing. Some parents would state that “He/she is not disabled. He/she manages” varying the meaning that informants attached to disability. The rest of the children who could not manage activities of daily living (ADLs), were taken care of and well looked after.

3.2. Perceived causes of disability

Many informants believed causes of disability to be witchcraft (*kuloyiwa*), or ancestors' sorrow or anger (*mizimu*), causes originating in disturbed social relations. These perceived causes place the blame of the disability on a curse, punishment or a gift, largely absolving the child and the parents (especially the mother) from taking the blame for the child's disability. Witchcraft was said to occur due to rifts in close relationships in the community (because of envy or other causes). Ancestor's sorrow was seen to be more of a passing character or “bad luck” which can be corrected; and that the logic behind it is that a dead relative would not want to harm their descendants as much as would someone practicing witchcraft. The cure for the disability is to deal with the underlying social rift. One grandmother in her 40s stated;

Disability is caused by witchcraft or when the family has not appeased the gods by brewing beer for them; or when the family killed someone years back and the spirit comes back to haunt the family by causing disability.

An example of disability seen as a curse is one young mother of a disabled child who believed that the cause of her child's disability was witchcraft;

My child was bewitched by my husband's 2nd wife. When I was pregnant I asked my husband if he could buy me a baby towel so as to carry the baby on my back after giving birth. My husband said he did not have the money then but would see if he could find some. My co-wife asked why I should ask for a towel when the baby was not even born. How do I know that I will have the baby? I did not understand this and so I kept quiet. The home birth was a difficult one; the baby had a cord round her neck and did not cry until the following day. At four months the baby could not sit independently, had no head control, drooled all the time and had a bent neck. My husband and I took the baby to the traditional healer and we were told that she had been bewitched. (Muderedzi, 2006)

An example of disability seen as punishment was given by the grandmother of a disabled child who explained that the cause of her grandson's disability was ancestor's sorrow. When asked to explain, she stated;

My daughter's husband had two wives and my daughter was the third wife. My son-in-law had not paid the two cows as dowry up till my daughter gave birth to the disabled child. After the child was born, the husband asked my daughter to leave his homestead stating that he could not afford to support her and the disabled child. According to our culture, non-payment of dowry could have caused the child to be born with a disability. We are now waiting to attend the headman's court for the case to be sorted.

The most important issue noted among all the informants after discovering the disability was "why" it happened. Witchcraft and ancestors' sorrow were the most common causes, but when no cause was found, the family saw the child as a gift, attesting the disability to "the will of God"; "natural reasons" or "it just happened". Children who were seen as gifts were commonly given names such as "*Twalumba*" meaning "we give thanks" or "*Chipego*", meaning "gift". Ten young informants (mothers), members of the Pentecostal and Catholic churches, reported to have taken the children first to their pastors for healing but later visited the traditional healers after family insistence and the need to know why the disability occurred. They reported that they then believed the cause of disability to be "God's will" but later reported the cause as witchcraft or ancestors' sorrow after the traditional healer visit. The rest of the informants (p. 43) had attended the traditional healer as the first port of call and reported the cause of disability as either witchcraft or ancestors' sorrow.

All the informants spoke of the importance of making offerings to the ancestors and their reliance upon them for protection. They reported making regular offerings to their ancestral spirits whether or not they were involved in any misfortune and there are certain occasions that call for regular offerings. This was noted during occasions such as changes in location from one homestead to another, whereby offerings to the ancestors were made before leaving and settling into the new homestead. Lack of such offerings over a period of time was said to be neglect of the ancestors, which could cause punishment from the ancestors, resulting in misfortune, such as disability.

3.3. Reactions to disability

When asked to state their reactions on discovering their child's disability, the researcher noted the different reactions of the informants consisting of young mothers, from that of the older mothers and grandmothers. The 10 informants consisting of young mothers made statements such as;

"It was a crisis"; "a great tragedy"—"I cried a lot"—"We were not expecting to have a disabled child"—"I had feelings of anger"—"How will I manage?"—"It was painful (*moyo wakoovoloko-zakatichisa*)"—"I did not talk to anyone for a long time".

When asked again during follow up visits, the same young mothers explained that things were getting better, as exemplified by one of the mothers;

We are alright and managing. The family helps with care. It is not a crisis anymore (laughs). It is one of those things that happen in life.

Older mothers, grandparents and the extended family's sentiments were echoed by one mother stating;

Having a disabled child is a life event. It is one of those things that happen in life. Anyway, it is better to have a disabled child than no child at all.

I grew up with a disabled sibling who was epileptic as well and we used to help my mother take care of her. She has a child and the child is now looking after her.

One male informant, the father to an 8 year old boy with muscle weakness, stated;

He is my only son. It is painful for me because who will look after me and my wife when we are old? I shall have to take another wife.

Our observations during funerals of disabled and non-disabled children showed not much difference in parents' reactions to the death of their children. On further enquiry, one old lady stated;

A disabled child can as well provide the family with children who can in future look after its parents and grandparents—every child is valuable.

3.4. Beliefs and attitudes

Previous life experiences were an important source of influence on the informants' attitudes and beliefs towards disability. All the 53 informants alluded to having had a disabled family member before, either in the immediate or extended family and some families were looking after their disabled child as well as a disabled older relative. They reported their lives in general as a struggle and that having a disabled family member did not make any difference. The social and psychological patterns that were laid down before the child with disabilities was born seemed to influence their perceptions and attitudes towards disability. The Tonga desire many children for they see in this the only way of offsetting the high child mortality, secure a continuous labour force for the household, support and care for aging parents and secure the continuation of the family. As a result of this, informants' attitudes towards disability were seen to differ in that those whose children had some degree of difficulty had a positive attitude and saw their children as future helpers at home and useful members of the community.

On social expectations one grandfather stated;

He has been our only grandchild for the past four years, now he manages to walk a little and helps with milking the goats. He helps a little in the house and he is great company.

Parents of a 12 year old girl stated;

She is useful around the house. She manages to wash plates and fetch water with her siblings. Our only fear is that she can be raped if she walks off on her own as a result she has to be with a family member all the time.

Parents of children with muscle weakness often stated;

I do not see any future for the child. I see a future filled with problems all the time. She is not independent in any way.

He is not capable of doing anything for himself, but still he keeps us company.

He is not capable of helping himself at all. The Catholic sisters through my brother who works in Bulawayo offered to take him to St Francis home for children with disabilities in Bulawayo but my husband and I refused because he may not be well looked after. He is happy here with us and his siblings. Infact we hear that children at a home are sometimes not well looked after.

He needs to be attended to all the time. We can manage but worry about him after me and my husband dies. Of course the siblings will take care of him but we still worry.

Siblings' sentiments on disability showed "love and a caring attitude", for example one sibling stated;

We don't mind that our brother is disabled. We play with him and help our mother look after him. Our friends come to play with him as well.

A few disabled children who were able to communicate were asked to state their feelings towards disability and treatment by their families and the community. Mobility was the most important function wished for followed by education and jobs. They reported lack of community stigmatization and discrimination. One disabled child stated;

Being disabled is not a good thing. I just wish I were able to walk and be with my friends and help with family chores like my other siblings. My family, friends and most people in the community like me.

One extended family member stated;

We are not the first or last to have a disabled child in the family. We all help each other when needed. It's one of those things that happen in life.

Physical disabilities received more positive attitudes than various other conditions. Physically disabled children, deaf, blind and intellectually disabled were noted to be with their peers carrying out activities of daily living such as fieldwork, looking after domestic animals, fetching water, firewood as well as wild fruits for consumption. They were much appreciated for their part in household chores. On the other hand, children with multiple disabilities were noted to be well taken care of despite them not managing any ADLs; with one mother stating;

A child is a child—It is better to have a disabled child than a dead one.

The Tonga proverb, "*Kocilema kunywigwa maanzi*" meaning "*it is better to be disabled than dead*", meant that it was better to have a disabled child than a dead one. The researchers did not encounter courtesy stigma when the extended family or neighbours were referring to the "disabled family". There was no relationship between social position and attitudes meaning that disabled children with similar impairments were treated the same despite differences in social positions of the disabled child and their family. This was noted through the chief's disabled grandchildren, the headman's and informants' children. The informants did not report much "emotional labour", that is when a person is hiding or changing their feelings in an attempt to show a more "acceptable" emotional front to those around them. The attitude portrayed was that they were not the only ones with a disabled child and that they would cope.

When asked about their experiences of community attitudes towards their children, most informants gave positive comments such as one mother stating; "You just take good care of him/her and sooner we will find a husband or wife for him". A few informants, particularly fathers of disabled children, gave negative comments, such as a young father stating; "Disability comes from your side (the mother's) of the family". One young mother stated, "*bayangizwela—life emakhaya inzima sibili*", meaning that the community felt pity for her and that life in the villages was very tough. This was from a young informant who had moved far from her relatives resulting in not much help from the extended family.

Teasing and laughing about the child's disability was reported and noted as coming from the mother of the child's kinsmen (bamutala). This act is allowed and was not taken by the informants to be hurtful. In this case the women make disability jokes about their relative's child with disabilities. This included practical jokes such as mimicking the child's mobility problems, difficulties in talking, feeding or blindness. The belief is that such an act helps the mother cope with the disability when other people talk about it.

It was noted that from birth, Tonga children with disabilities were perceived as part of the family. They went through the same cultural rituals as their counterparts with no cases of hiding except for one incident which according to the research assistant seemed like a case of hiding but was found to be a case of a mother overprotecting her baby due to lack of support and knowledge. This was a family living all alone in the mountain area far from other homesteads and the extended family. Focus group discussions revealed cases of leaving a disabled child locked up in a hut in cases where the mothers had to fetch water, firewood or working in the fields. This was reported to take place for short periods when there were no siblings or extended family to look after the child at the homestead.

4. Discussion

The Ingstad and Sommerschild (1983) model for coping with disability offers a theoretical framework to help understand and explain the ways Tonga informants viewed and coped with disability. It integrates cultural and contextual approaches to disability and offers us a way to understand the rationale behind the families' and caregivers' strategies and decisions with regards to the care of the disabled child. It also brings out the interactional approach which sees the disabled child interacting with his/her environment filled with physical, attitudinal, communication and social barriers. The model further adds to the analysis of family, community and cultural issues, such as ethno-medical beliefs, past life experiences, personality factors and socio-economic variables.

The study findings showed that the Tonga did not blame themselves for a child's disability, which may have been an important factor towards them taking care of the child without hiding or mistreatment. Their understanding of disability was equated with incompetence, meaning that a disabled person is someone who is unable to look after him or herself practically or physically, and is thus dependent on others for support. Despite equating disability with incompetence, disabled children were generally accepted, and primarily considered and valued. They showed acceptance for disability, and no fear for the "abnormal", and saw disability as unfortunate. Stigmatisation of both the disabled child and the family was not noted. The cultural and contextual approaches as well as the social construction of disability brought out disability perceptions that were shaped by context and culture, revealing both positive and negative attitudes.

The importance of Tonga belief in spirits of their ancestors and their role in their lives should not be underplayed. Tonga cultural beliefs still dominate understanding about the causes and implications of bodily impairments (Munsaka, 2012; Siamwiza, 2013). Like other African societies as well as other parts of the country, the Tonga had the same explanations of disability causes, why the disability happened and traditional healer involvement in dealing with the causes. Witchcraft and ancestors' sorrow primarily originated in disturbed social relations. As a result the most effective prevention against disability was to care for and manage social and divine relations (Ingstad, 1997; Muderedzi, 2006; Shuttleworth & Kasnitz, 2005; Talle, 1995). The results showed all the participants having visited or were to visit the traditional healer.

Retrospective information from the river Tonga interestingly showed how even when disabled children were said to have been killed, some had survived (noted in songs and folktales) and were well taken care of. This is similar to what was found in studies among the Karanga in Zimbabwe and the Chagga of East Africa which found discrepancies between what was said and done in those communities (Edgerton, 1970; Jackson & Mupedziswa, 1988). In the current study, the research assistant who had worked with the communities for over 30 years, stated one incidence of "alleged" hiding which was infact an act of lack of knowledge on how to care for the child. The child was reported to have been well looked after and healthy. This could be a case of a negative practice found in poverty and lack of choices rather than negative perceptions of disability, as has also been argued in previous research (Eide, Khupe, & Mannan, 2014).

Similar to other African societies, as well as other parts of Zimbabwe, the river Tonga stated that infanticide did take place, giving reasons for such acts as protection of their communities from

droughts, breakouts of diseases and other misfortunes. They however reported that a redefinition of personhood took place due to high infant mortality back in the valley and this has continued up to date. It was interesting to note that in their case, infanticide did not stop due to Christian intervention or government policy but through an excessively high prevalence of child mortality in the valley. This was also noted by Swift and de Graaf (1994) and Colson (1970) with Swift and de Graaf stating that the Tonga lived in a terrible state with 60–80% child mortality due to lack of vaccinations, malaria, diarrhoea and other illnesses. Our study also suggests a high mortality of 23 out of 30 children under the ages of five years old in the first cohort, resulting from food shortages, malnutrition and lack of access to healthcare (Muderedzi, 2006).

However, sixty years later after the forced evictions, the poor socio-economic situation still prevails with food shortages, malnutrition and lack of access to healthcare. Being an agricultural society resulted in the need to desire many children as more children meant more manpower, support in old age and political power as children grow to adulthood. This resulted in the Tonga embracing the disabled child and offsetting the high child mortality. Despite lack of Christian intervention a disabled child was said to be a gift from God or “it just happened” when no cause was found, making it easier to accept the disabled child. Unlike other parts of the country where mothers are blamed for the child’s disability (Curran & Runswick-Cole, 2013; Marongwe & Mate, 2007), the mothers were absolved from wrong doing, resulting in the family staying together and supporting the disabled child without feelings of guilt or shame. A solution such as taking another wife, a system of resource access helping a family to meet their needs was noted.

Similar Shona and Ndebele disability proverbs as well as the Tonga proverb “kocilema kunywigwa maanzi” meaning “it is better to be disabled than dead”, still prevails with the Tonga stating that a disabled child was more appreciated than not having a child at all. Generally, custom prescribed that people with disabilities should be well treated. The rest of the proverbs show kindness and respect to the disabled, with the disabled child perceived as a human being and integrated into society. Tonga perception of disability as “one of those things that happen in life” seemed to put the issue of disability into the open and a phenomenon that they have all learnt to live with. Generally, personhood depended more on social identity and the fulfillment of family obligations than on individual ability. Children with some form of mobility, the deaf, blind and intellectually disabled were appreciated for their household contributions such as taking care of domestic animals and field cultivation. Some were appreciated in that they kept the family company as well as having their own children with the family’s help through arranged marriages or to just have a child who would help take care of the family, making the disabled person a useful member of the family. This was not a case of productive people being better than the non-productive but perhaps a survival strategy. The researchers witnessed a number of cases of arranged unions that enabled the disabled adult to have his /her own family with positive results.

As a result, attitudes seemed to vary according to the families and how they perceived the disabled child’s activities of daily living. To the Tonga, a disabled child was seen as “a child is a child”, life was seen as superior to death and that disability was a secondary matter. The child was not regarded as a disabled child, but a child with a disability.

As has been found in previous studies (Ingstad & Sommerschild, 1983), it appears that previous life experiences in coping with critical life events such as famines or high infant mortality were of major importance in handling the issue of disability. This was noted by informants’ reactions to the child’s disability. The difference between the young and older mothers showed experience and non-experience of difficult life situations. Reactions to disability were not reported as rejection and no forms of abuse were seen or heard of during researcher visits as well as during some unexpected visits on the way to other informants. Family and community psychosocial support was noted through visits, sickness, funerals and other social gatherings. Children with disabilities were seen around engaging in all sorts of activities with their peers; with the exception of the severely disabled who were at home and found mainly outside under the ngazi (hut on stilts) shade with the males

carrying out activities such as wood carving the well-known Tonga stools and females weaving baskets. The child with disability was a social being from birth.

5. Conclusion

In Zimbabwe there is little research on parents' perceptions and treatment of disabled children especially from chronically poor remote rural ethnic minorities such as the Tonga. Therefore this paper fills the gap. It appears that the Tonga hold both positive and negative attitudes towards disability. The complexities could be due to factors such as their history, past and present life experiences, social, cultural and economic situation. We note the importance of culture and discursive factors in the framing of the meaning of disability as (Goodley & Swartz, 2016; Tremain, 2005) stated that the conceptualisation of disability depends heavily on the kinds of place within which disability emerges. It was noted that high infant mortality as well as the high prevalence of disability in these communities equally contributed to a more accepting attitude as a part of a "normalisation" process. The findings highlight the importance of addressing indigenous knowledge in disability research as a means of understanding and addressing the needs of disabled children and their families. It was noted how disabled children were not getting equal access to healthcare, education, employment opportunities, disability related services and experienced exclusion from everyday life activities. Therefore the findings are important for government policy designing and implementation since disability is now understood as a human rights issue. There is need for the adoption of the United Nations Convention on the Rights of People with Disabilities (Convention on the Rights of Persons with Disabilities, 2006) into a new government policy on disability. The information is also important for academic and policy debates on disability and care giving. It is also important to people in practice working for government, non-governmental organisations, private as well as other developmental organisations to improve on the lives of people with disabilities.

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