

**Lived Experiences of Parents/Guardians of Children with Neuro- developmental  
Disorders: Concept Paper**

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**Abstract**

Parents /Guardians of children with Neurological Disorders encounter physical, psychological, social and financial negative experiences throughout their process of parenting children with neurological deficit.

**Methodology**

Walker and Avant (2011) concept analysis model was used as a guide. Literature search was done using the following search engines, Google Scholar, PubMed, and Medline and 43 articles which

ranged from 1994– 2017 were identified. The researchers settled for 30 articles that were found relevant to the concept of interest.

## **Results**

Lived experiences were not clearly defined in the articles reviewed even though they start from birth or from the period around birth and this involve living with the child continuously.

## **Conclusion**

Analysis of lived experience of parents/guardians of children with neurological disorders could broaden health carer's knowledge on the psychosocial and medical needs of parents or guardians of children with neurological disorders through curricula changes.

**Key words:** Parent/guardian, children with neurological disorders.

## **1.0 Introduction and Background**

When parents are expecting a baby they anticipate having a normal baby at birth. The birth of a child or discovery that a child has disability is an intense and traumatic experience. In a study carried out in Swaziland by Twala et al.,(2015) the parents of children with disabilities have the same expectations as other parents of children without disabilities. The discovery at birth that the child is somehow abnormal can be devastating for parents. The initial reaction of parents maybe numbness. A parent's reaction may be negative, influencing stress levels and adaptation which maybe similar to bereavement (Blachar & Bakar, 2007; Hassall et al., 2005). A questioning period follows and may persist for years, as to why it would have happened to them. There may be a tendency for parents to blame themselves or each other (Scorgie & Sobsey, 2000).The diagnosis of the disability of the child may result in some parents reacting negatively both physiologically and emotionally. Parents /guardians of a child living with disability undergo a transition with

significant changes in social life. Some parents/guardians experience considerable stress and in addition depression, anger, shock, guilt, denial and confusion (Heiman, 2000). In concurrence Reeja Mol & Sujatha (2013) in a study carried out in India, stated that parents react differently to their child's impairment some accept more easily whereas for other parents this signifies isolation, chronic sorrow and feeling isolated. Hence, the time needed for adjustment and the sequence differs with each parent/guardian.

Parents of children with disabilities experience greater stress and challenges in care giving such as health problems, greater feelings of restriction and higher levels of depression in comparison to the parents of children without disability (Hassal et al., 2005). Willingham & Storr, (2014) carried out a study in the United Kingdom on parents caring for a child with intellectual disabilities: A UK perspective. The study suggests among other things that services offered do not always address these needs of the parents.

### **1.1 Challenges faced by Parents/ Guardians of children with Neuro-developmental disorders**

Woodgate et al., (2015) corroborated that parents/guardian of children with complex care needs have added challenges and responsibilities resulting in alterations in roles including the nursing role to ensure child wellbeing and survival. Some parents encounter difficulties in accessing financial assistance and inadequate support from other family members and communities.

Families of children with special needs have to adjust to the presence of the child in addition to coping with the normal demands and stresses of family life. In most African cultures disability is perceived as hopeless, helpless and curses in the society and these beliefs have not made it easier for parents / guardians. According to Twala (2014), in the African context from early history disabilities are associated with evil in corroboration Abosi (2001) stated that most of these negative beliefs and attitudes are a result of misconception and lack of proper understanding of disability.

Consequently the negative attitudes prove to be a stumbling block for acceptance of the disabled by negatively affecting the parents/guardians.

### **1.2 Problem Statement**

Literature neither clearly defines nor fully describes the concept of lived experiences. There is no tool to guide the exploration of lived experiences of parents/guardians of children with neuro-developmental disorders.

### **1.3 Objective**

The objective of this paper was to explore the meaning and implications of lived experiences of parents/guardians of children with neuro-developmental disorders.

### **1.4 Identifying uses of the concept**

Firstly the study results can be used to educate nurses, doctors and other service providers about the experiences and the unique needs of parents/guardians of children with neuro-developmental disorders. Secondly the results would influence policy makers to improve the care and services for parents/guardians caring for children with neuro-developmental disorders. Thirdly, the results would identify gaps for further research in the care of children with neuro-developmental disorders.

### **1.5 Methodology**

This concept of lived experiences was guided by Walker and Avant concept analysis framework. Steps of the concept analysis are Selection of a concept, Identification of aims/purpose of analysis, Significance and uses of the concept, determining the defining attributes, identification of the model case, Identification of additional cases, Identification of antecedents and consequences and Defining empirical referents.

The criteria utilised for inclusion of articles was articles from health and related studies on lived experiences of parents of children with neurological disorders.

### **1.5.1 Data sources**

The search engines used as data sources were Google Scholar, Pubmed, Medline Phrases and words utilised in the search were lived experiences, parents, guardians, children and neurological disorders.

Inclusion criteria: The papers used were from both developed and developing countries as lived experiences have no geographical boundaries

### **1.5.2 Study selection**

Review of literature on lived experiences of parents/guardians of children with neuro-developmental disorders was done to establish the definitions of lived experiences since the concept is difficult to measure, not well described and to define the attributes of the concept of lived experiences. Descriptions were classified into themes with similar characteristics

## **1.6 Defining Attributes**

The characteristics that appear repeatedly are the attributes of a concept (Walker and Avant, 2011). Attributes in this concept paper are the indicators of lived experiences of parents/guardians of children with neurological disorders and they are as follows:-

### **1.6.1 Age Parameter**

A child is from birth to 18 years of age in Zimbabwe and in other countries it is 21 years of age but a child with a neurological deficit remains a “child” after the legal age of majority due to dependency on the parents/guardian.

Some of the articles talked about the shock and feelings associated upon birth of the abnormal child or delivery of the information to parents that the child has a neuro-developmental disorder

months or a couple of years after birth. In addition the child is the same age as peers but lags behind because of delayed development whereas peers may be at the university (Mol & Sujatha, 2013, Hamendanchi, et al., 2016).

### **1.6.2 Time factor**

Parent/s, guardian of child with neurological deficits live with the child with neuro- developmental disorder continuously from birth or from around the period of birth. The articles searched do not clearly bring out the time factor or duration of exposure with the child. Lived experiences of the parent /guardian involve living with the child continuously from birth or around birth. The articles discuss the overwhelming demands of parenting and complexities of bringing up a child which is more marked with a child with a neuro- developmental disorder. Some of the demands increase with age of the child (Mol & Sujatha, 2013, Woodgate et al., 2015, Cuskelly et al., 2017).

### **1.6.3 Knowledge and skills of caring for the child**

In the articles parents felt they were ill- equipped with regards to knowledge and skills, and coping with looking after the child (Woodgate et al, 2015, Willingham- Storr, 2014, Gona et al., 2011).

### **1.6.4 Negative experiences and emotional baggage of having a child with neurological deficits**

The articles indicated shattered dreams and the grief experienced by parents as the “death of a perfect child” that was anticipated and the associated social isolation and stigmatisation (Thwala et al., 2015, Kearney, 1994, Hamdenchi et al., 2016, Willingham –Storr, 2014, Gona et al., 2011).

## **1.7 Defining antecedents**

### **1.7.1 Identifying Antecedents**

**These include:-**

Pregnancy

Hereditary

Developmental disorders during pregnancy

Environmental hazards

Maternal age and diseases like diabetes mellitus

Ultra sound scan of pregnancy revealing some of the fetal abnormalities

Unknown outcome of the pregnancy

Genetic counselling

Parity - first or multipara

Birth of a child with neurological deficits

## **1.8 Consequences**

### **18.1 Non acceptance of an abnormal child**

When parents are expecting a child, in their minds their anticipation is a perfect child for whom they have aspirations of doing fairly well or excelling in life. On the contrary the birth of a child with some form of disability or a child who exhibits disability later parental cherished dreams are crushed resulting in pain and grieving for the “death of a perfect child who was existent in their minds” (Gona et al., 2011; Twala et al, 2015; Reeja Mol & Sujatha, 2013).

Parents are shocked by the diagnosis of the child this is followed by disbelief, frustration, denial, anger, stress, knowledge deficit, fear, (Gona et al., 2011; Twala et al., 2015; Reeja Mol& Sujatha, 2013).The psychological trauma caused by the birth of the disabled child may result in persistent feelings of confusion throughout life. According to Twala et al., (2015) parental recovery from the loss would be dependent on one’s capability for separation from the lost dreams. In addition the parents may go through emotions like depression, guilt or blaming each other feeling that they are responsible for the child’s predicament because of excessive alcohol use, genetics, spiritual curse or some other logical or illogical reasons. The parents’ mental health and psychological

functioning is affected adversely resulting in conditions like anxiety or depression (Cuskelly et al., 2017)

### **1.8.2 Life style changes**

According to a study by Woodgate et al., (2015) in Canada the birth of an abnormal child or child diagnosed later as abnormal necessitated changes in the family lifestyles due to increased time demands with the child. The family life was disrupted as changes in routines had to be implemented. Cuskelly et al., (2017) concurred that the parents may find the child's temperament and behaviours demanding. In addition there is less time for self, couple time, and family vacation is adversely affected. The care needs of the child tend to be labour intensive and time consuming depending on the degree of disability, the care needs may include bathing, dressing, feeding, changing of diapers (Woodgate et al., 2015; Reeja Mol & Sujatha, 2013).

**1.8.3 Physical** illnesses related to stress like hypertension, peptic ulcer diseases and other psychosomatic illnesses to include labour intensive- burnout.

### **1.8.4 Social Isolation**

Some parents suffer from stress due to the demanding parenting role whereby they feel isolated overwhelmed with responsibility and entrapped (Cuskelly et al., 2017). The social isolation that comes with having a child with that disability parents/ guardians are faced with include: - isolation, stigmatisation, friends become fewer with some supportive and some not, and seclusion from community functions. In some cultures like in the African context the children were given derogatory names implying they were less human. Some parents expressed that their situation was not well understood by the extended family which isolated them as well (Willingham- Storr, 2014; Gorlin et al., 2016; Twala et al., 2014). In corroboration Gona et al., (2011) highlighted that the



carers of children with disabilities repeatedly expressed feelings of being stigmatised, discriminated and excluded from numerous activities in their lives.

### **1.8.5 Social support**

Parents of children with intellectual disabilities relied on the family members to take turns in assisting in day today activities. Support from the family members enabled some of the parents to maintain their jobs or to carry out other activities (Woodgate et al. 2015; Willingham-Storr, 2014; Reeja Mol & Sujatha, 2013). Continual support for the parents/guardians is necessary right from the birth of the child.

### **1.8.6 Information deficit**

Parents/guardians expressed hunger for information on several areas pertaining to the care of the child, health, education, behavioural needs, financial counselling and other services available for the child whom they have little experience or knowledge about. The parents become lifelong learners in search of information to improve the quality of life of their child. (Woodgate et al., 2015; Reejah Mol & Sujatha, 2013). According to Woodgate et al., (2015) parents become more confident, empowered and acquire new skills in the process of knowledge acquisition

**1.8.7 Economical-** Issues concerned included:- medical costs, giving up job for mother, lack of resources to facilitate care, lack of fees for special needs school, and unavailability of special needs school within proximity place of residence and transport costs

## **1.9 Results**

A literature review of 30 articles was done from 1994 to 2017 in a period of three, weeks from 3<sup>rd</sup> to the 27<sup>th</sup> of August 2017. Thirty-three articles were discarded. The final sample was (n= 11) was made up of articles from nursing, medical, social sciences and other health related disciplines.

**Figure 1**

No.	Author	Year	Sample size	Population
1	Woodgate et al.	2015	40	Parents of children with complex care needs
2	Twala et al.	2015	20	Parents
3	Gona et al.	2011	20 10 05 35	Carers Community members Teachers Total sample
4	Willingham- Storr, G.M.	2014	13	Articles
5	Reeja Mol, R. & Sujatha, R.	2013	7	Mothers of children with Down's syndrome
6	Gorlin et al.	2016	22	Family –severe autism
7	Cuskelly et al.,			
8	Hassall, R., Rose, J. & McDonald, J. (2005).	2005	46	Parenting Stress in mothers
9	Cuskelly, M., Hauser-Cram, P. & Van Riper, M.	2017		Families of children with Down syndrome
10	Abosi, O.C.	2000		Trends and Issues
11	Hamedanchi et al.,	2016	10	Parents 5 man and 5 women

## **2.0 Discussion**

Three articles discussed the birth of an abnormal child (Reeja & Mol, 2013, Thwala et al., 2015, Kearney, 1994). Most of the articles reviewed discussed the lived experiences without the antecedents to lived experiences outlined earlier in the study.

Parents of children with neurological disorders are discharged home without adequate information on how to care for the children. In addition there was no standard follow up care for the parents to assess how they are coping bio- psychosocially.

Most of the authors indicated that the parents/guardians initially underwent the shock of having such a child and impacted on the time it took to accept the child. In addition the parents were not fully equipped to deal the child' ever increasing demands psychologically, socially, economically and physiologically. Some of the family and marital relationships were also affected negatively.

### **2.1 Operational definition**

The researchers' operational definition of lived experiences involve parents or guardians living with a child with neurological disorder continuously from birth or from around the period of birth who suffer the psychosocial, economic and physiological effects of having such a child in their lives.

#### **2. 1. 2 Definition of Lived Experiences**

Lived experience is defined as the "personal knowledge about the world gained through direct, first- hand involvement in daily events rather than through mere observation or hearsay (Oxford, 2015). The definition to some extent has the attribute of first hand involvement on a daily basis as opposed to second hand information but the aspect of timing from birth or from around birth or before birth as advised by scan results is missing.

“Lived experience as it is explored and understood in qualitative research, is a representation and understanding of a researcher or research subject’s human experiences, choices, and options and how those factors influence one’s understanding of a perception of knowledge”. (Given, 2008). This definition brings out the experience part but the lived part is missing but it does bring out how the experiences have a bearing on perception of knowledge about living in the situation. Synonyms for lived experience- life- world, meaning- making, intentionality (Roget’s 21<sup>st</sup> Century Thesaurus, 2013).

### **2.1.3 Live (experience)**

Live is defined as having “first- hand knowledge of states, situations, emotions, or sensations” (Mimidex, 2008-2013). This definition tallies with some attributes with regards to having first-hand knowledge about what it is like to live with a child with neuro- developmental disorder including the emotions and feelings involved.

### **2.1.4 Experience**

Experience is defined as “practical contact with and observation of facts or events/the knowledge or skill acquired by a period of practical experience of something” (Oxford Dictionary, 2015).

The definition of experience explains some of the attributes that the parent/guardian has acquired some skills and knowledge from the practical experience from direct contact with the child but it does not explain the time factor from birth or from around birth or before birth as advised by scan results.

Experience

Direct personal participation or observation; actual knowledge or contact/ a particular incident, feeling, etc, that a person has undergone.

Synonym- feels (Collins Dictionary).

Some- how the definition given for experience does have the attribute of being directly involved with actual knowledge and feelings about the care but lacks the time frame and the birth part.

Lived experience is defined as the “subjective perception of one’s experience of health or illness. Associated with Rosemarie Parse’s Nursing Theory of Human becoming, universal lived experiences are people’s perceptions of their personal health-related experiences” (Medical Dictionary, 2009).

### **2.1.5 Child**

According to WHO a child is a person who is 19 years or less unless the national law defines one to be an adult at an earlier age. Those in the 10 - 19 age groups are classified as adolescents

The convention of the rights of the child defines a child as a person below the age of 18 unless the law of the country states otherwise by setting the legal age of adulthood earlier (UNICEF, 1990).

### **2.1.6 Child with Neuro-developmental disorder**

Neuro-developmental disorders are disabilities involving the nervous system and the brain involving impairment in neurological functioning that affect cognitive or motor skills and behaviour. The conditions include attention deficit hyperactivity disorder, intellectual disability, Down’s syndrome, autism, cerebral palsy (American Heritage Dictionary, 2016).

### **2.1.7 Parent**

A parent is a mother and/or a father but can be inclusive of guardian, folks, ancestor, author, begetter (Roget’s 21<sup>st</sup> Thesaurus 2013). The definition explains parenthood but does not specify the parenthood of a child with neurological deficit.

### **2.1.8 Guardian**

A guardian is a custodian, nurse, keeper, protector, baby sitter and is inclusive of a chaperone, overseer and warden (Roget's 21<sup>st</sup> Thesaurus 2013). The definition given explains custodianship without being explicit about the child with neurological deficit.

## **3.0 Impacts**

### **3.1 Non acceptance- an abnormal child**

Three articles by Gona et al., (2011); Twala et al, 2015;Reeja Mol & Sujatha,(2013) described the impact on the parents upon discovering the child is not the “expected perfect dream child”. When parents are expecting a child, in their minds their anticipation is of a perfect child for whom they have aspirations of doing fairly well or excelling in life. On the contrary the birth of a child with some form of disability or a child who exhibits disability later, parental cherished dreams are crushed resulting in pain and grieving for the “death of a perfect child who was existent in their minds”(Gona et al.,2011:Twala et al.,2015;Reeja Mol & Sujatha,2013).

### **3.2 Life style changes**

Three articles by Woodgate et al., (2015); Reeja Mol & Sujatha, (2013) focused on lifestyle changes the parents/guardians had to go through during the care of the child due to the condition of the child.

### **3.3 Social isolation**

Four articles by Willingham- Storr, (2014); Gorlin et al., (2016); Twala et al., (2014) & Gona, et al., (2011) focused on social isolation by the extended families, and the community experienced by parents/guardians of children with neurological disabilities.

### **3.4 Social support**

Only three articles by Woodgate et al. (2015); Willingham-Storr, (2014); Reeja Mol & Sujatha, (2013) highlighted the support that parents got from family members inclusive of siblings and grandparents of the disabled child who took over multiple roles and responsibilities assumed by the care giver.

### **3.5 Information deficit**

Two articles by Woodgate et al., (2015); Reejah Mol & Sujatha, (2013) highlighted that parents had knowledge deficit on the day to day care of the child, available services and education issues pertaining to the child.

### **3.6 Constructing a model case**

Mrs X is a 35 year old married pregnant woman with three daughters. Mrs X gives birth to a live baby boy and the couple is ecstatic .The boy child is named Junior. The couple struggles with Junior, as his milestones are delayed in comparison to the older children. In addition he doesn't eat well, he still cannot talk sensibly at the age of four. Junior has tantrums which are difficult to control which can be very embarrassing in public places. Mrs X had to quit her teaching job to look after her son. Extended family members think he is a spoiled child. He appears to be in his own world. After assessment by the paediatrician the couple's hopes and dreams are shattered after being informed Junior has a severe grade autism spectrum disorder. Junior needs to be reviewed regularly at the hospital.

#### **3.6.1 Analysis of a model case**

The couple's dreams of a perfect boy child with a bright future are shattered. The boy needs constant supervision and care in activities of daily living as a result the mother had to quit her job impacting negatively on the family finances. The family social life and life in general is disrupted. The extended family regards the boy as spoiled.

### **3.6.2 Borderline case**

Mr and Mrs B are very pleased with the birth of their baby girl Caroline after three years of failing to conceive. The couple's happiness is watered down by the doctor who informs them that their baby girl has a neuro-developmental disorder. However Mrs B collapsed and died a couple of days after giving birth. Mr B decided to take Caroline to Children's home where she has been living for the past two years. Mr B visits his daughter at the Children's home whenever he can and takes her to spend the weekend at home every four months.

### **3.6.3 Analysis**

The couple had a baby with a neuro- developmental disorder but after the mother's demise the baby was taken to a Children's home. Mr B who was the surviving parent visited the child at the home periodically and only took her home on weekends every four months. Mr B had no lived experience of continuously living with or caring for the child.

### **3.6.4 Contrary case**

A young couple Mr and Mrs C had a baby boy Christopher a year after marriage. The couple was informed by the doctor that the baby has club feet. Although the couple was disappointed they were relieved when they were told that their child's disability could be corrected. Christopher's clubfeet were corrected and his milestones were normal.

### **3.6.5 Analysis**

Although the couple had lived experience of a child with a disorder it was short lived and not a neurological disorder. The disorder was corrected and the child had normal milestones.

### **3.7 Empirical Referents**

Empirical referents are the means of measuring or recognising the defining characteristics or attributes. In other words they are not tools to measure the concept (Walker and Avant, 2011). In



the context of this study the empirical referents are a history of being a parent/ guardian continuously living with a child with a neurological disorder from birth or from around the period of birth of the child and for as long as the child are alive.

### **3.8 Conclusion**

This concept was undertaken to clarify the meaning of lived experience of parents/guardians of children with neurological disorder and to promote consistency in use of the concept in nursing education, practice and research concept clarification is useful to health care practitioners in assessing the physiological and psychological needs of parents/guardians and children with neuro-developmental disorders respectively in order to support them.



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