



**THE EXPERIENCE OF RAISING A CHILD WITH DOWN SYNDROME:
PERCEPTIONS OF CAREGIVERS IN KWAZULU-NATAL**

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(Successful Solutions Training in Child Development., 2013).

Abstract

Introduction: Due to limited research within KwaZulu-Natal there is a deficit in the knowledge base and understanding surrounding the dynamics of caring for a child diagnosed with Down syndrome. The study aims to inform health professionals who adopt a psychosocial approach, such as occupational therapist, in an effort to improve the therapy and handling of the caregivers and children.

Methodology: A sequential explanatory mixed method approach with an interpretive phenomenological perspective was utilized. Sampling utilized non-probability methods from the Down syndrome Association (KwaZulu-Natal) database. An initial quantitative descriptive survey (n=57) guided the subsequent qualitative phase encompassing focus groups and interviews (n=18). Quantitative data was statistically analyzed using SPSS (version 21) and the transcribed quantitative data utilized thematic analysis with in vivo, emotions and descriptive coding.

Results and Discussion: Experiences were primarily influenced by initial reactions of the participants; their level of knowledge of the syndrome and reactions to informing their family and community. Thereafter the positive and negative aspects of raising the child affected their perceptions.

Conclusion: Many factors contributed to the participants' perceptions of raising a child with Down syndrome, namely: community and family attitudes; support structures available; positive factors such as personal growth as well as negative factors such as the erratic health of the child and difficulties with inter-personal relationships. However; an overall positive perception was reported by the participants, with an emphasis on advice to other caregivers based on lived experience.

Key words: Down syndrome, Caregiver, Community, Challenges, Perception

Table of contents

Supervisors' permission to submit for examination	i
Declaration	ii
Plagiarism Declaration	iii
Acknowledgements	iv
Abstract	v
List of Tables	xii
List of Figures	xiii
Abbreviations	xv
Operational Definitions	xvi
Down syndrome	xvi
Caregiver.....	xvi
Coping.....	xvi
Stress.....	xvii
Perceptions	xvii
Experiences	xvii
Intervention	xviii
Health Professional	xviii
Subjective.....	xviii
Community	xviii
Family.....	xix
Attitude	xix
Challenges	xix
CHAPTER ONE: Introduction	1-8
1.1 Introduction	1
1.2 Background.....	2
1.2.1 Down syndrome: An overview	2
1.2.2 Caring for the child with Down syndrome	2
1.3 Research Problem Statement.....	3
1.4 Research Question	4

1.5 Aim.....	4
1.6 Objectives	4
1.7 Type of study and method	4
1.8 Rationale.....	5
1.9 Framework.....	6
1.9.1 Theoretical Framework.....	6
1.9.2 Conceptual Framework	7
1.10 Outline of the study	7
1.11 Summary	8

CHAPTER TWO: Literature Review.....9-24

2.1 Introduction	9
2.2 The history of Down syndrome: The progression.....	9
2.3 What is Down syndrome?	10
2.4 What causes Down syndrome?	12
2.5 How does a child with Down syndrome develop?	12
2.6 Prevalence in South Africa: How common is Down syndrome?	13
2.7 Impact on caregivers: the experience, perceptions and coping strategies	15
2.8 Caregivers and their family: is there an impact?.....	19
2.9 Additional resources needed when raising a child with Down syndrome...	19
2.10 Education and Down syndrome: integration into society.....	20
2.11 Attitudes in South Africa.....	21
2.12 Support and acceptance.....	22
2.13 The need for understanding.....	23
2.14 Summary.....	24

CHAPTER THREE: Methodology.....23-54

3.1 Introduction.....	25
3.2 Research approach and design.....	25
3.3 Phases of research.....	27
3.4 Phase one: Quantitative design.....	28

3.5 Phase two: Qualitative design.....	29
3.6 Relationship of phase one phase two.....	30
3.7 Rationale for the choice of the research design.....	31
3.8 Recruitment and selection of participants.....	31
3.8.1 Population.....	32
3.8.1.1 Phase one.....	32
3.8.1.2 Phase two.....	32
3.8.2 Sampling technique and size.....	33
3.8.2.1 Phase one.....	34
3.8.2.2 Phase two.....	35
3.8.3 Participant Inclusion Criteria.....	36
3.9 Data Collection Instruments.....	37
3.9.1 Phase one: Descriptive survey.....	38
3.9.2 Phase two: Focus group and interviews.....	39
3.10 Pilot Study.....	40
3.10.1 Piloting the descriptive survey.....	40
3.10.2 Piloting the focus groups and interview questions.....	41
3.11 Data collection method.....	41
3.11.1 Phase one: Descriptive survey.....	41
3.11.2 Phase two.....	42
3.12 Data analysis.....	43
3.12.1 Phase one: Descriptive survey.....	43
3.12.2 Phase two: Focus group and interviews.....	43
A. Process one: Reduction of data.....	44
B. Process two: Display of data.....	44
C. Process three: Drawing and verifying conclusions.....	44
3.13 Quality Inference.....	46
3.13.1 Credibility.....	47
3.13.2 Reliability and trustworthiness.....	47
3.13.3 Accuracy.....	48
3.13.3.1 Accuracy of language for phase one and phase two.....	48
3.13.3.2 Accuracy of the tools.....	48
3.13.3.2.1 Phase one.....	49
3.13.3.2.2 Phase two.....	49

3.13.3.3 Accuracy with participants.....	49
3.14 Ethical considerations.....	49
3.14.1 Autonomy.....	50
3.14.2 Divulging of subjective information.....	50
3.14.3 Consent.....	50
3.14.4 Research process.....	51
3.14.5 Confidentiality.....	51
3.14.5.1 Anonymity of participants.....	51
3.14.5.2 Storage of important information and documents.....	52
3.14.5.3 Confidentiality relating to the Researcher and Co-facilitator/ Interpreter.....	52
3.14.6 Access to research study results.....	52
3.14.7 Beneficence.....	52
3.14.8 Nonmaleficence.....	53
3.14.9 Justice.....	53
3.14.10 Benefit and risk.....	53
3.14.11 Referral.....	54
3.15 Summary.....	54

CHAPTER FOUR: Results.....55-89

4.1 Introduction.....	55
4.2 Phase one: Demographics.....	55
4.3 Phase one: Findings.....	56
4.3.1 Graphical representation.....	56
4.3.2 Summary of quantitative findings.....	64
4.4 Phase two: Demographics.....	64
4.4.1 Getting to know the participants.....	65
4.4.1.1 Focus group one.....	65
4.4.1.2 Focus group two.....	65
4.4.1.3 Individual interview.....	66
4.4.1.4 Dyad interview.....	66
4.4.1.5 Triad interview.....	66

4.5 Phase two: Findings.....	67
4.5.1 Theme one.....	68
4.5.2 Theme two.....	71
A. Positives.....	72
B. Negatives.....	74
4.5.3 Theme three.....	77
A. Positives.....	78
B. Negatives.....	79
4.5.4 Theme four.....	82
A. Positive reactions.....	82
B. Negative reactions.....	83
4.5.5 Theme five.....	85
4.6 Summary.....	88

CHAPTER FIVE: Discussion.....90-107

5.1 Introduction.....	90
5.2 Discussion.....	90
5.2.1 Initial Response, What is Down syndrome?.....	90
5.2.2 Understanding. How does Down syndrome happen?.....	92
5.2.3 Feelings toward the child.....	93
5.2.4 The positive factors of raising the child with Down syndrome.....	95
5.2.5 The negative factors of raising the child with Down syndrome.....	97
5.2.6 International versus National: A comparison.....	103
5.2.7 Advice to other caregivers.....	105
5.3 Summary.....	106

CHAPTER SIX: Conclusion.....107-120

6.1 Introduction.....	108
6.2 Limitations.....	108
6.3 Significance of the study.....	108
6.4 Recommendations.....	110

6.5 Conclusion.....	111
6.6 References.....	113

APPENDICES.....122-185

1. Explaining the study to possible survey participants (English).....	121
2. Explaining the study to possible survey participants (isiZulu).....	123
3. Explaining the study to possible focus group participants.....	125
4. Explaining the study to possible focus group participants (isiZulu).....	127
5. Profile questions for the focus group (English).....	129
6. Profile questions for the focus group (isiZulu).....	130
7. Proposed survey (English).....	131
8. Proposed survey (English) Coded.....	138
9. Proposed Focus group questions and Prompts.....	146
10. Request for Permission from The Down syndrome Association KwaZulu-Natal once Ethical clearance has been granted.....	147
11. Proposed survey (isiZulu).....	150
12. Proposed Focus group questions with the motivation.....	158
13. Proposed Focus group questions (isiZulu).....	159
14. Nvivo 10 Node report.....	160
15. Translator’s curriculum vitae.....	163
16. Letter of Consent (English) Participants.....	168
17. Letter of Consent (isiZulu) Participants.....	170
18. Gatekeeper Permission.....	172
19. Confidentiality agreement Researcher.....	173
20. Confidentiality agreement Interpreter/ Co-facilitator.....	174
21. Getting to know the participants (focus groups & interviews).....	175
22. Proposed request for Permission from Hospital CEOs.....	180
23. Proposed request for Permission from Hospital CEOs (2).....	182
24. Copy of the proposed Questions to be given to the participants.....	183
25. Copy of the proposed Questions to be given to the participants (isiZulu)...	184
26. Turnitin similarity percentage after review.....	185

List of Tables

Table 3.1	Representation of the research question in relation to the descriptive survey.....	39
Table 3.2	Representation of the research question in relation to the focus groups and interviews.....	40
Table 4.1	Relationship of positive and negative responses to the experience of raising a child with Down syndrome.....	63
Table 4.2	Focus group one.....	65
Table 4.3	Focus group two.....	66
Table 4.4	Strong independent mom.....	66
Table 4.5	United couple.....	66
Table 4.6	Mom, daughter and domestic worker; a formidable team.....	66

List of figures

Figure 3.1	Diagrammatic representation of the research approach utilizing the Explanatory Sequential Design.....	27
Figure 3.2	Phases of the study.....	28
Figure 3.3	Development of the descriptive survey.....	29
Figure 3.4	Formulation of the qualitative questions.....	30
Figure 3.5	Example of how phase one data is expanded in phase two.....	31
Figure 3.6	Diagrammatic representation of the Population.....	33
Figure 3.7	Sampling technique: Phase one.....	35
Figure 3.8	Diagrammatic representation of the inclusion criteria phase one.....	37
Figure 3.9	Diagrammatic representation of the inclusion criteria phase two.....	37
Figure 3.10	Data analysis using Nvivo (version 10) software package.....	46
Figure 3.11	Diagrammatic representation of the process.....	51
Figure 4.1	Initial reactions to discovering that the child has Down syndrome...	57
Figure 4.2	Initial feelings toward the child.....	58
Figure 4.3	Initial level of knowledge/understanding of Down syndrome.....	58
Figure 4.4	Participants' knowledge of how Down syndrome occurs.....	59
Figure 4.5	Participants' knowledge of intervention options available initially in relation to currently.....	60
Figure 4.6	Emotions experienced when considering telling their family and community.....	61
Figure 4.7	Possible difficulties experienced with family members as a result of the child.....	62
Figure 4.8	Emotions experienced as a result of caring for a child with Down syndrome.....	63
Figure 4.9	Represents participants' access to resources.....	64
Figure 4.10	Themes.....	67
Figure 4.11	Theme one.....	68
Figure 4.12	Theme two.....	71
Figure 4.13	Theme three.....	77
Figure 4.14	Theme four.....	82

Figure 4.15 Theme five..... 85

Abbreviations

KZN	KwaZulu-Natal
SPSS	Statistical Package for Social Scientists
CEO	Chief Executive Officer
AMA	Advanced Maternal Age
ICD	International Classification of Diseases

Operational Definitions

Down syndrome¹:

A congenital disorder, as a result of an additional 21st chromosome, whereby the affected person has mild to moderate cognitive impairment, short stature, a flattened facial profile as well as other physical features. Down syndrome is also referred to as **trisomy 21** (Ward, 2002).

Caregiver

Stedman (2006) defines this as “A specific individual, such as a parent, foster parent, or head of a household, who attends to the needs of a child or dependent adult.”

For the purpose of this study, a caregiver will be defined as any individual that predominantly cares for the basic needs and wants of the child, e.g. a sibling, grandparent etc, irrespective of the presence or absence of biological parents.

Coping

"Constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing" or "exceeding the resources of the person". (Lazarus and Folkman, 1984).

¹ Down Syndrome, Down syndrome, Downs syndrome and Down's syndrome are used synonymously within this research. The researcher has chosen the term Down syndrome due to its frequent appearance in research literature reviewed BUCKLEY, S. J. & SACKS, B. 2001. An overview of the development of children with Down syndrome (5-11 years). . *Down Syndrome Issues and Information* [Online]. Available: <http://www.down-syndrome.org/information/development/childhood/>, CUNNINGHAM, C. C. 1996. Families of children with Down syndrome. *Down syndrome research and practice.*, 4, 87-95, FIDLER, D. J. & NADEL, L. 2007. Education and children with Down syndrome: Neuroscience, development, and intervention. *Mental Retardation And Developmental Disabilities Research Reviews*, 13, 262 – 271, HODAPP, R. M. 2007. Families of persons with Down syndrome: New perspectives, findings, and research and service needs. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 279-287, KING, L. A., SCOLLON, C. K., RAMSEY, C. & WILLIAMS, T. 2000. Stories of life transition: Subjective well-being and ego development in parents of children with Down syndrome. *Journal of Research in Personality.*, 34, 509–536, LAM, L. & MACKENZIE, A. E. 2002. Coping with a child with Down syndrome: The experiences of mothers in Hong Kong. *Qualitative Health Research.*, 12, 223-237, LAMPRET, J. C. & CHRISTIANSON, A. 2007. Reproductive choices made by South African mothers who have a child with Down syndrome. *South African Medical Journal.*, 97.. In addition The Down syndrome Association (KwaZulu-Natal) readily utilises this naming of the condition.

For the purpose of this study, coping refers to the participants' methods, strategies or techniques used to attempt to overcome those situations or circumstances that cause them stress in relation to raising a child with Down syndrome.

Stress

"Any emotional, physical, social, economic, or other factor that requires a response or change." (Kearney, 2003). Examples include changing jobs, schools or moving house (Hodapp, 2007).

This definition relates to raising a child with Down syndrome as a response or a change is needed in order to care for the child.

Perceptions

"The process by which an organism detects and interprets information from the external world by means of the sensory receptors" as well as "insight or intuition gained by perceiving," (William Collins Sons, 2009). "To achieve understanding," (Houghton Mifflin Company, 2009).

For the purpose of this study, perception denotes to the caregivers' 'interpretation' or 'understanding' of what the world means in various situations. It relates to their subjective analysis of the experiences that they encounter which may or may not be influenced by a multitude of factors that comprise of 'the external world.'

Experiences

"Direct personal participation or observation" that results in "accumulated knowledge," or "The faculty by which a person acquires knowledge of contingent facts about the world, as contrasted with reason,"(William Collins Sons, 2009).

In this study, experience denotes to both 'knowledge' that has been gained by the care givers over the time of raising the child with Down syndrome as well as the current experiences of the care givers as a result of their 'participation' in daily life and care for these children.

Intervention

“Any interference in the affairs of others,” (William Collins Sons, 2009).

The ‘interference’ within the context of the study denotes to assessment and therapy strategies utilized by Health Professionals with regards to the lives of their clients. The term intervention within this context is one of a positive and assisting nature and serves to enhance the lives of the caregivers and children with Down syndrome in some way.

Health professionals

“A person trained to work in any field of physical or mental health,” or “A person who helps in identifying or preventing or treating illness or disability,” (American Psychological Association (APA), n.d.)

This denotes to all those health care workers that would come into contact, assess and treat either the caregiver or the child with Down syndrome. Thus Occupational Therapists, other Therapists, Medical Doctors, Social Workers, Psychologists and the like are all included.

Subjective

“Of, relating to, or emanating from a person's emotions, prejudices, etc,” or “Belonging to, proceeding from, or relating to the mind of the thinking subject and not the nature of the object being considered,” (William Collins Sons, 2009).

In this case, subjective relates to the care givers’ **own** feelings and emotions, ones that ‘belong’ to them relating to their personal experiences. These feelings/emotions may or may not be influenced by others but they are not considered the feelings/emotions of any other person other than that specific individual.

Community

“The people living in one locality,” or “A group of people having cultural, religious, ethnic, or other characteristics in common,” (William Collins Sons, 2009).

In relation to the study, the community relates to those people who live in and around the area in which the care giver and child lives. They may or may not have the same culture, religion, ethnicity and the like in common yet they do share their demographics

Family

“A primary social group consisting of parents and their offspring, the principal function of which is provision for its members,” or “A group of persons related by blood; a group descended from a common ancestor,” (William Collins Sons, 2009). Within the context of KwaZulu-Natal, families are often considered to be beyond that of a nuclear environment consisting of the parents and children. For this reason and the purpose of this study, the definition of a family not only entails those who are related by a direct blood line but also the extended family.

Thus in addition, the definition may also encompass “all the persons living together in one household,” (William Collins Sons, 2009). Or by extension, for the purpose of this study; those individuals who care for the child with Down syndrome as if they were family.

Attitudes

“The way a person views something or tends to behave towards it, often in an evaluative way,” (William Collins Sons, 2009).

This relates to those views as perceived by the care givers themselves, their community and their families. It is the way that the individuals feel about Down syndrome, the child, the caregivers, the level of care given and so on and as a result, their actions toward the caregivers, family and or child.

Challenges

“Something that by its nature or character serves as a call to battle, contest, special effort” or “Difficulty in a job or undertaking that is stimulating to one engaged in it,” (American Psychological Association (APA), n.d.).

In terms of this study, the aspects of increased effort or difficulty experienced by the caregivers, community and family will be explored. It will encompass any facets that cause a sense of complexity in the lives of these individuals.

CHAPTER ONE

INTRODUCTION

1.1 Introduction

This chapter presents a brief history and progression of Down syndrome in terms of development and understanding of the condition. It explores decreased knowledge with regards to the syndrome within the South African and more specifically the KwaZulu-Natal context. Furthermore it allows for the participants' experiences to be explored in order to increase awareness of the difficulties and the benefits of raising a child with Down syndrome as well as the barriers and limitations experienced.

For the purpose of this study, the title of caregiver denotes those individuals who predominantly care for the child with Down syndrome, which may result in the role being shared e.g. between a mother and a grandmother. By utilizing participants that predominantly care for the children rather than just parents, it allows for a more accurate representation of the lives of these individuals within the KwaZulu-Natal Province.

There is limited research related to raising a child with Down syndrome in the South African context (Rajh, 2005), particularly within KwaZulu-Natal. Therefore this research will provide insights into the experience of caring for a child with Down syndrome. In addition it will aid in supplementing the pool of knowledge of Occupational therapists and other and other health professionals that assess and provide interventions to children with Down syndrome.

Although physical characteristics and health difficulties have been identified and found to be similar in individuals with Down syndrome, many aspects of the syndrome are not yet comprehensively understood. Particularly the dynamics of interpersonal relationships and the coping mechanisms used by those with whom they live need further exploration. Through the researcher's clinical experience, it has become apparent that many individuals within KwaZulu-Natal lack a sufficient

knowledge base with regards to not only what Down syndrome is, but also the effect raising such a child can have on the family and community.

Undertaking research within South Africa, more specifically within KwaZulu-Natal, will increase the knowledge base of health professionals providing caregiver support and thereby contribute to improving the process of caring for a child with Down syndrome.

1.2 Background

This section provides an overview of Down syndrome as well as caring for such a child.

1.2.1 Down syndrome: An overview

Ward (2002) describes the diagnosis, now known commonly as Down syndrome, which has changed from the original derogatory 'Mongolian Idiocy' in 1961. The official term 'Down syndrome' was acknowledged by the World Health Organization in 1965 (Ward, 2002). In 1965, the syndrome itself was largely misunderstood resulting in decision to label those affected with the dehumanizing term of "Mongolian idiots", based upon the Mongolian features of their eyes and their intellectual impairment. Although many advances have occurred within research and the modern human comprehension of this syndrome, there are still many aspects of the syndrome that are misunderstood (Ward, 2002). Individuals with Down syndrome are usually classified in terms of their physical characteristics that are considered unique to the syndrome. When Down syndrome was first identified it was found that their physical attributes were so similar that the individuals could have easily been considered to be family members (Ward, 2002).

1.2.2 Caring for the child with Down syndrome

Despite the South African Constitutional Rights (Constitution of the Republic of South Africa, 1996), affected children are still discriminated against, which is often related to a lack of understanding about the condition (Lansdown, 2002). This lack of knowledge extends to what is required when raising a child with the syndrome, both emotionally and in terms of material resources.

Within the South African context, prejudice and judgment remains pervasive when considering children who are not 'normal' or developing typically (Botha et al., 2006, Lansdown, 2002). Culture is a large factor governing the reactions and attitudes of the community (Penn et al., 2010, Mhlanga, 2013). The community often attributes the occurrence of congenital disorders to curses, religious misdoings and failure of the parents which only fuels stigmatization (Lansdown, 2002, Mhlanga, 2013, Penn et al., 2010). As a result, these children are often kept hidden away from the judging public, which violates their human rights when access to health care services are denied (Lansdown, 2002).

Family involvement is paramount to children's development, especially those who require additional care (Cifra-Bean et al., 2012), with the lack of a family unit impacting negatively on the child. However, family involvement is not at all times constructive and positive, highlighting the need to protect children from harmful family dynamics (Thomlinson 1996, as cited in Goba, 2009).

In addition to the negative attitudes toward the child on a physical level, behavioural complications have been noted in individuals with Down syndrome, which are partly due to the intellectual deficits that these individuals experience (Goba, 2009). Such complications include "anger, aggression, fighting, inability to take responsibility and poor academic performance" (Goba, 2009). This contributes to the stress of inter-personal relationships, especially those of the individual's caregiver, due to their need to care for the physical, emotional and psychological needs of the individual with Down syndrome on a daily basis (Lam and Mackenzie, 2002).

1.3 Research Problem Statement

To date, limited studies have been done to explore the perceptions, attitudes, experiences and coping strategies of caregivers raising a child with Down syndrome in South Africa that could be used to inform intervention strategies for health professionals.

1.4 Research Question

What are the perceptions, experiences, attitudes and coping strategies of caregivers of children with Down syndrome as well as the community attitudes and how can these be used to inform intervention strategies for health professionals.

1.5 Aim

To explore the perceptions, experiences and coping strategies of caregivers of children with Down syndrome in order to inform intervention strategies for caregivers and children with Down syndrome by health professionals.

1.6 Objectives

The study had the following objectives

- I. To describe the subjective positive and negative experiences of caregivers who raise children with Down syndrome.
- II. To describe the community attitudes as perceived by the caregiver toward themselves and the child.
- III. To highlight the family attitudes and challenges as perceived by the caregiver.
- IV. To explore the caregivers' coping strategies (mental and behavioural methods) used to overcome the stress of raising a child with Down syndrome.
- V. To highlight this information so that it may be utilized to inform intervention strategies of health professionals.

1.7 Type of study and Method

This study is a mixed method design within an explanatory sequential strategy (Creswell et al., 2003). As a result the study is divided into two phases, the first being quantitative and the second qualitative.

Phase one involved a descriptive survey with closed-ended questions that would guide the qualitative phase due to the sequential nature of the design (Creswell et al., 2003). Phase two was qualitative and followed an Interpretative Phenomenological Framework (Williams, 2007) with a Psychodynamic perspective (Marshall et al., 2004) in the conduction of the focus groups and interviews.

1.8 Rationale

The purpose of this mixed method study was to explore the dynamics surrounding raising a child with Down syndrome in terms of lived experiences of the caregivers. With increasing research in and around children with Down syndrome, there is the hope that a greater understanding will develop in terms of how to adequately incorporate these children into society; decrease the cases of neglect; ensure that rehabilitative intervention is optimized to enhance quality of life for both the child with Down syndrome as well as his or her caregivers, and to help to increase the statistics of successful experiences of both the children and the caregivers.

The lack of relevant research available within the South African context, and specifically within Kwazulu-Natal (Rajh, 2005) highlights the need for a greater understanding regarding the emotional responses and reactions of those caregivers who have previously or are currently raising a child with Down syndrome (Thomlison et al., 1996). Furthermore, the limited available research often includes only the parents of the individuals with Down syndrome rather than including their caregivers, thus increasing the knowledge deficit in this country.

As the study is being conducted in KwaZulu-Natal, the researcher endeavours to explore the reactions and experiences of the diverse caregiver population of this area. This will allow for the participants' experiences to be explored within the relevant cultural contexts to increase awareness of the challenges and the benefits of raising a child with Down syndrome as well as the barriers and limitations experienced.

By researching participants that care for the children rather than just parents, realities in the lives of individuals within KwaZulu-Natal are accommodated. Clinically, the researcher has found the parents often have work demands or are absent from the child's life and thus the study allows for those participants that care for the child to voice their perceptions.

This research will aid in obtaining knowledge and assist in a better understanding of the dynamics surrounding the care of a child with Down syndrome. This will aid

in the knowledge base of Occupational therapists and other health professionals that assess and provide intervention to children with Down syndrome.

This study may also provide insight into highlighting coping strategies, the use of support groups and stress management skills that are lacking amongst the participants and those with similar experiences (King et al., 2000). In this way the study will allow for further research to be conducted, increased intervention strategies to be identified and further exploration into assisting caregivers of children with Down syndrome (Boyd, 2002).

1.9 Framework

The theoretical and conceptual frameworks are explored below, namely the Phenomenological Framework and the Psychodynamic Perspective.

1.9.1 Theoretical Framework: Phenomenological Framework.

An Interpretive Phenomenological framework (van Manen, 2007) was used in phase two of the study in order to understand the experiences and perceptions of the participants regarding caring for Down syndrome children. Phenomenology allows for non-prejudicial data to be utilized without the control of theoretical concepts and taints. In essence it allows for the participants' voice to be heard in their own way without influence from the research process (van Manen, 2007, Reiners, 2012).

The participants' views were explored both on a conscious and at times a subconscious level, by delving into what they experienced (Williams, 2007). This framework, by virtue of its focus on phenomena related to the topic of study, will enable health professionals to gain a better understanding of the dynamics surrounding raising these children. The intention is for the results to supplement their holistic approach when treating these children, and to assist them to be sensitive to the caregiver's situation as a result of understanding their experience on a daily basis.

1.9.2 Conceptual Framework: Psychodynamic Perspective

The psychodynamic perspective is directed toward the interaction of individuals within a small group, such as a focus group, which provides a platform for unresolved problems and sharing experiences (Marshall et al., 2004). The use of the Psychodynamic Perspective allows for meaningful results to be obtained through the formation of themes that will allow for subjective perspectives to be conveyed (Marshall et al., 2004).

As the focus groups and interviews were conducted by the researcher, this framework guided the researcher in terms of obtaining subjective data that was later categorized into themes. In addition, participants were referred to a counselor as the information divulged was of a sensitive nature.

1.10 Outline of the Study

Chapter Two presents the Literature Review, and addresses the issues of:

The history of Down syndrome; what the syndrome is; the etiology; how the child develops as well as the prevalence within KwaZulu-Natal. Furthermore the impact on caregivers is explored; the resources needed to raise the child and the attitudes within South Africa. The chapter concludes with support and acceptance as well as the need for understanding.

Chapter Three outlines the Methodology that guides the study, and indicates the study population; sample size; methods used to collect manage and analyze the qualitative and quantitative data.

Chapter Four presents the Results

Chapter Five presents the discussion including the integration of both qualitative and quantitative results found in chapter four.

Chapter Six presents the conclusion; significance of the study; limitations and recommendations.

1.11 Summary

The limited research regarding the experiences of care givers of Down syndrome children in South Africa highlights the need to understand the dynamics surrounding care and improve insight into this syndrome. This will not only assist the caregivers, their family and their community, but health professionals who provide advice and guidance to these individuals on a regular basis. It is essential to ensure that health professionals are able to empathize with the caregivers in order to offer the most appropriate intervention possible. In addition, understanding the dynamics of the caregiver-child relationship is vital, as it influences other factors such as stress, coping, degree of support needed and their general quality of life.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

From the literature reviewed, it is apparent that there is a considerable amount of research available internationally on Down syndrome. The available literature mostly from United States of America and United Kingdom (Beresford et al., 2007, Buckley and Sacks, 2001, King et al., 2000, Lam and Mackenzie, 2002, Lazarus and Folkman, 1984, Kearney, 2003, Cifra-Bean et al., 2012) provides knowledge about the impact of this condition both upon children and caregivers, albeit not within the context of KwaZulu-Natal. Availability of current research both nationally and internationally was noted to be limited, thus explaining the use of older literature, which further supports the need for additional studies. The review presents various factual aspects of the syndrome such as the history of Down syndrome and the progression of what, the etiology as well as what the syndrome is and the prevalence within the South African context. To allow for a greater overall concept of the syndrome, the chapter explores how the child develops, impact on caregivers and their family, attitudes in South Africa, resources needed to care for the child and the need for further understanding.

2.2 The history of Down syndrome: The progression

In 1965, the term Down syndrome was officiated by the World Health Organization (Ward, 2002). Previously individuals with this syndrome were referred to as those with Mongolian Idiocy and worse they were referred to as Mongolian Idiots, a term derived from the Mongolian appearance of their eyes. John Langdon Down was later appointed as the Medical Superintendent at the Royal Earlswood Asylum of Idiots (Ward, 2002), during which time he began to examine individuals with what appeared to be similar characteristics.

He found such a prominent link between individuals on both a physical and psychological plane that he stated that they appeared to come from the same family. "So marked is this that when placed side by side it is difficult to believe that the specimens compared are not children of the same parents," (Lansdown, as

cited in Ward, 2002, 2). In addition to his physical documentations, Langdon Down also noted aspects such as an inco-ordination amongst these individuals; a decreased life expectancy; as well as a remarkable ability to be trained (Ward, 2002).

In 1959, Lejeune and his peers identified the characteristic that lead to the presentation of Down syndrome both physically and cognitively, chromosome 21 (Ward, 2002:3). Since then, minimal additions to identified characteristics have been recorded apart from a few facial characteristics including skin folds of the eyes, placement of the ears as well as a single simian crease present on the palm of the individual (Sherman et al., 2007).

Prenatal screening was introduced in the 1970's as a way to determine if the fetus would be born with Down syndrome. This method was particularly used in cases whereby advanced maternal age (AMA) was present as a standard in the public health system in South Africa. This test is known as amniocentesis and is offered to all women who are considered to be advanced in age entirely free of charge as part of the South African National Policy (Urban et al., 2011). This method is particularly effective when access to fetal ultrasounds is restricted, or when biochemical screening is not an option (Naidoo et al., 2011). However, the reliability is questionable as a false positive is possible, resulting in expecting mothers experiencing undue stress.

2.3 What is Down syndrome?

Down syndrome is one of the leading causes and most commonly identified form of cognitive impairment as well as an array of physical characteristics and biological deficits (Sherman et al., 2007). This definition serves to summarize the characteristics and gene abnormalities found when examining an individual with Down syndrome, which occurs when there is a duplication of chromosome 21. This results in the typically reported physical features; cognitive deficits such as memory and thought process delays, receptive and expressive speech impairments; behavioural dysfunction as well as health conditions which often affect the individual's heart and lungs (Silverman, 2007). According to the 2012 International Classification of Diseases (ICD-10-CM Diagnosis Code Q90.9)

(World Health Organization, 2011) the following definitions are used when characterizing Down syndrome:

- I. A chromosomal abnormality consisting of the presence of a third copy of chromosome 21 in somatic cells.
- II. A disorder caused by the presence of an extra chromosome 21 and characterized by cognitive impairment and distinguishing physical features.
- III. Clinical manifestations include hypotonia, also known as flaccidity; short stature; protruding tongue; small ears; short, broad hands; an additional finger (clinodactyly); simian crease; moderate to severe cognitive impairment; a wide range of other defects, such as congenital heart diseases; respiratory disorders and leukemia, may be associated.
- IV. Down syndrome patients who survive into late adulthood may develop Alzheimer syndrome.

Furthermore there are three main categories of Down syndrome namely: Trisomy 21; Mosaic and Translocation. Trisomy 21 is most common followed by Mosaic and lastly the least common, Translocation (Boulet et al., 2008, National Down Syndrome Society., 2012, healthplus24.com., 2013, Jyothy et al., 2002).

Trisomy 21 occurs due to abnormalities in cell division for chromosome 21 during development of the embryo and thus the child presents with those characteristics, both physically and cognitively, associated with the syndrome (Jyothy et al., 2002, Ward, 2002, Sherman et al., 2007, National Down Syndrome Society., 2012) Mosaic type occurs due to co-existence of typical and atypical chromosomal cells thus these children present with the least amount of physical and cognitive manifestations (Jyothy et al., 2002, healthplus24.com., 2013, Ward, 2002, Sherman et al., 2007, National Down Syndrome Society., 2012). Lastly Translocation is linked to Trisomy 21 as part of the 21st chromosome detaches and reattaches with another chromosomal cell thus these children also present with the manifestations as seen with pure Trisomy 21 (healthplus24.com., 2013, Jyothy et al., 2002, Ward, 2002, Sherman et al., 2007, National Down Syndrome Society., 2012).

2.4 What causes Down syndrome?

Although the exact factors are unknown when examining the causative elements that result in Down syndrome, certain determinants have been reported to contribute to giving birth to a child with this syndrome (Sherman et al., 2007, healthplus24.com., 2013). These risk factors include advanced maternal age, which include those individuals who are close to menopause, as well as very young mothers. Other factors have also been proposed including: genetic predisposition; hormonal imbalances and instability of chromosomes. (Penrose, 1933, Jyothy et al., 2002, National Down Syndrome Society., 2012).

Research has discovered over 300 genes present within chromosome 21, and it is the over-expression or the duplication of these genes, as well as the gene interactions that occur, that result in physical and functional abnormalities in these individuals. The multitude of interactions that could occur between the extra genes provides insight into the characteristics and impairments that occur with the syndrome (Penrose, 1933, National Down Syndrome Society., 2012, O'Connor, 2008, Jyothy et al., 2002, Down Syndrome: Parents Sharing., 2014).

New developments in research have proposed that the over-expression of genes that occur in individuals with Down syndrome may in fact be linked to tissue type. Thus it is possible to propose that the over-expression of genes if synchronized with brain growth, and development could account for the degree of cognitive impairment and severity of functional limitations (Silverman, 2007, Down Syndrome: Parents Sharing., 2014, Jyothy et al., 2002, O'Connor, 2008).

2.5 How does a child with Down syndrome develop?

According to Silverman (2007), research has indicated that initially, the brain and skull development of the embryo to the fetal stage in those with Down syndrome is what would be considered normal, when compared to embryonic development of those without the syndrome. However; at approximately 22 weeks of gestation in those with Down syndrome, changes begin to occur in terms of the 'normal' developmental pattern of the fetus which are irrefutable by the six month mark (Silverman, 2007). These abnormalities include decreased development of the brain and brainstem, whereby they appear smaller than expected, as well as

severely underdeveloped auditory processing centers that could be linked to the hearing and language difficulties that these individuals experience (Silverman, 2007).

Infant development in Down syndrome has been shown to be parallel with those of 'normal' infants in terms of memory and learning (Silverman, 2007, Down Syndrome: Parents Sharing., 2014). In both infants with Down syndrome and those without, the brain areas that allow for more mature learning to occur only begin to truly develop some time after birth. The fact that these structures within the brain develop at a much slower rate greatly affects the learning ability of infants with Down syndrome (Silverman, 2007, Down Syndrome: Parents Sharing., 2014, healthplus24.com., 2013).

It has been shown that through the use of extensive training and repetition, individuals with Down syndrome are able to acquire skills at relatively the same milestone period as infants without the syndrome (Cifra-Bean et al., 2012, Down Syndrome: Parents Sharing., 2014). The challenges are however; that although infants with Down syndrome acquire the skills, the execution and performance of these skills is somewhat variable and at times influenced by decreased motivation (Fidler and Nadel, 2007). Inconsistent development and retention of skill leads to acquisition and loss that cannot be predicted,(Fidler and Nadel, 2007, Down Syndrome: Parents Sharing., 2014).

2.6 Prevalence in South Africa: How common is Down syndrome?

In South Africa, limited resources, poor 'communication' and 'access' (Rajh, 2005) are some factors that have negatively impacted on research (Rajh, 2005, Mhlanga, 2013). South African research into the prevalence of Down syndrome is lacking, as available statistics generally reflect population groups such as mental or physical disability as a whole without specificity (Lehohla, 2001).

The 2001 South African census was the last to include various disability statistics including type and severity (Lehohla, 2001). The most recent South African census of 2011 does not include these statistics as it no longer includes the disability specific questions related to both mental and physical impairment as seen in the

1996 and 2001 censuses (Statistics South Africa, 2012). The 2011 South African census instead includes general abilities, well being and the use of assistive devices such as glasses, walking devices and medication (Statistics South Africa, 2012). The 2011 census focuses on the barriers to participation as a gauge of dysfunction rather than identifying the type of disability as seen in 2001 (Statistics South Africa, 2012, Lehohla, 2001). For this reason, namely the shift in approach, the 2011 South African census cannot be compared to the earlier censuses (Statistics South Africa, 2012). In the 2011 census, above 90% of the participants reported no limitations that restricted activity participation (Statistics South Africa, 2012). This does not serve to highlight the percentage of physical and mental impairment but rather indicate if difficulties exist and whether participants are able to engage in daily tasks.

In terms of the 2001 South African Census, 2 255 982 people were recorded as having different forms of disability in the country. In addition, it was reported that the Free State Province was most affected, with 6.8% of the disabled population, whilst Gauteng was least affected with 3.8% of the population experiencing various forms of disabilities. Physical disability, as a broad and vague category, was ranked the second most prevalent type of disability (30%), with intellectual and communication disabilities being ranked fifth (12%) and sixth (7%) respectively (Lehohla, 2001). As previously discussed, Down syndrome involves a multifaceted manifestation that includes elements of physical, mental and communicative impairments, and thus it is possible that these children/adults could have been included in any of the statistical groupings described above, hence making it difficult to categorically state the prevalence of the syndrome in SA. Mental impairments that are related to the diagnosis of Down syndrome are ranked third in the overall South African burden of diseases (Department of Health, 2012).

While research surrounding Down syndrome is limited in South Africa, a prevalence study by Naidoo et al (2011), indicated that approximately 1 in every 600 children is born with Down syndrome, resulting in a high incidence rate. This is comparable to the United States, where approximately 1 in every 800 – 1,000 children are born with Down syndrome (Cifra-Bean et al., 2012).

These figures indicate the need to gain a better understanding of the syndrome, and particularly its impact on the lives of those it affects. Thus it is necessary to adopt a social or psychosocial model approach to understand the dynamics that surround individuals with Down syndrome (Creswell, 2007, Mhlanga, 2013).

2.7 Impact on caregivers: the experience, perceptions and coping strategies

Within the context of this study, the title of caregiver is awarded to those individuals who care for the child with Down syndrome for the most amount of time. In some instances, this may be more than one person where this role is shared e.g. between a mother and grandmother. Therefore, this study will not only include the parents of these children, but broaden the criteria to ensure that the cultural dynamics that are present within KwaZulu-Natal are represented. The role of caregiver is challenging, it requires the person to care for the child in all senses of the word, thus ensuring that their basic needs are fulfilled (Gcaza and Lorenzo, 2008, Mhlanga, 2013, Pillay et al., 2012).

In the 1980's, the previously negative perception of children born with Down syndrome began to evolve into what is considered the 'stress-and-coping perspective' (Hodapp, 2007). Hodapp (2007) also maintains that this perspective shifted thinking in the direction that having a child with a disability was to be considered a stress factor within the family rather than a definite negative event. Hodapp (2007) further related this stressor to the way in which a family would react to a change in their lifestyle. The family would, as a result, problem solve in the same way that they would if they were moving house or changing jobs (Jakobsson et al., 2007, Pillay et al., 2012). This highlights how families will deal with these stressors in their own unique way, based on their subjective comparison to what they consider is the norm (Diener et al., 1985, Pillay et al., 2012, healthplus24.com., 2013). This may result in the family either unifying or disintegrating (Jakobsson et al., 2007). Studies conducted internationally have reported findings that suggest that families who care for children with Down syndrome are no more affected than those families who raise children without the syndrome (Cunningham, 1996, King et al., 2000, Marchal et al., 2013, Down Syndrome: Parents Sharing., 2014).

Whilst pregnant, mothers begin to psychologically prepare themselves to give birth to a healthy child, and when the child is born with 'special needs', the mother may feel a sense of loss of that 'perfect' child (Lampret and Christianson, 2007, Lam and Mackenzie, 2002, Down Syndrome: Parents Sharing., 2014). There is then the need to come to terms with major life changes, which requires adapting to novel circumstances and experiences (King et al., 2000, Down Syndrome: Parents Sharing., 2014). According to the theory, the five stages of grief, proposed by Elisabeth Kübler-Ross (Kearney and Hyle, 2003), parents who have children with congenital disorders, such as Down syndrome, may often undergo emotional reactions as a result of the child's diagnosis (Kearney and Hyle, 2003). This subjective feeling is said to resemble that of bereavement, as the parents are mourning the loss of that 'normal' child (Kearney and Hyle, 2003, Down Syndrome: Parents Sharing., 2014, Pillay et al., 2012).

According to the theory, no two individuals go through the same experience. The progression of experiences will also differ in that the stages are not followed in a particular order. Instead, an individual may experience anger before denial or depression before bargaining, thus allowing for the individual to attempt to deal and cope with their grief in their own way (Kearney and Hyle, 2003, Down Syndrome: Parents Sharing., 2014). The parents of that child may enter an emotional process that will vary in intensity depending on multiple factors, such as the severity of the child's impairments; the emotional state of the parents; as well as the parent's ability to adapt and reach the fifth stage according to the theory, which is "acceptance" (Lam and Mackenzie, 2002).

According to Lam & Mackenzie (2002), it must also be noted that in the final stage of the theory proposed by Elisabeth Kübler-Ross, the individual has not necessarily come to terms with what has happened and is not always coping. Instead, this stage highlights the acceptance of the reality of the situation and that it cannot be changed. As with a caregiver of a child with Down syndrome, they must learn to accept that the diagnosis is permanent, and that it will eventually be considered the norm of daily life (Holland, 1996, Mhlanga, 2013, Marchal et al., 2013).

When a child is not what is considered 'normal' and does not develop in the standard manner, regardless of the degree of impairment, it results in additional demands placed on the caregiver/s (Jakobsson et al., 2007, Marchal et al., 2013, Down Syndrome: Parents Sharing., 2014). This is also the case when the child fails to meet the expectations of the caregiver/s and community in which they live (Rajh, 2005, Mhlanga, 2013). In South Africa, despite the Constitutional Rights (Constitution of the Republic of South Africa, 1996), these children are often deprived of the resources that they require, such as rehabilitation; health care; adaptive equipment and education which in turn further hampers their development (Gcaza and Lorenzo, 2008). In addition, stress is developed and maintained as the caregiver/s themselves often do not have the necessary 'resources' to cope with the demands placed upon them (Engelbrecht et al., 2001). They may lack the knowledge, attitude and even emotional ability to cope with the situation (Engelbrecht et al., 2001, Mhlanga, 2013, Povee, 2010).

When considering the stress experienced, factors can be both internal and external and can cause equal amounts of turmoil for the caregiver (Engelbrecht et al., 2001). Internal stress factors encompass the feelings, perceptions and attitudes that the caregiver themselves experience in response to caring for a child with 'special needs'(Engelbrecht et al., 2001). The stress is created by them, with the severity being determined by their own subjective experiences (Rajh, 2005).

External stress factors include the attitudes, perceptions and prejudice from others (Rajh, 2005, Mhlanga, 2013). This can also include the community in which the child lives, the general public or even other relatives (Engelbrecht et al., 2001, Mhlanga, 2013). Negative attitudes, barriers to participation and even stigmatization results in feelings of frustration and stress by the caregiver (Engelbrecht et al., 2001). The degree to which the stress affects the caregiver is partly regulated by themselves, in the sense that they can decide the amount to which the stress bothers them (Rajh, 2005). However; the severity of the stress is usually gauged depending on the intensity of the external forces (Rajh, 2005, Mhlanga, 2013). A combination of internal and external stress factors usually occurs, whereby the caregiver struggles not only with their own beliefs about the child, accompanied by the task of caring for them, but also the reactions of others,

which are often negative and somewhat abusive (Rajh, 2005, Pillay et al., 2012, Marchal et al., 2013).

A compounding factor reflected in studies is that children with Down syndrome show far more behavioural impairments when compared to the general population or their siblings (Menolascino, 1965, Pillay et al., 2012). They exhibit behaviours that are considered to be external traits when they are in their childhood years. These include being stubborn, inattentive and having concentration impairments, aspects of oppositional disorder, impulsivity and attention-seeking patterns (Pueschel et al., 1991). Thus, adding to the challenges experienced by those who care for the child (Menolascino, 1965). As the child grows older their behavior has been compared to the same behavioural patterns of individuals in adolescent and early adulthood stages, whereby they internalize their behaviours. This includes withdrawal from others and engaging in solitary tasks rather than interact with others, thus decreasing their integration into society (Pueschel et al., 1991).

Reports of positive and negative factors (Marchal et al., 2013, Mhlanga, 2013, Pillay et al., 2012) of caring for the child vary across studies. Quality of life and the perception of this has been linked to caring for a child with Down syndrome (Marchal et al., 2013). The quality is considered lowered when health difficulties; additional costs; adaptations to the caregivers' life and negative perceptions are concerned (Marchal et al., 2013, Mhlanga, 2013, Pillay et al., 2012). A good quality of life is reported in terms of availability of support and resources; acceptance and development of coping mechanisms (Marchal et al., 2013, Mhlanga, 2013)

Literature shows that the difficulties experienced when caring for the child based on the physical and cognitive challenges are often balanced by the joy and love gained from the child (Down Syndrome: Parents Sharing., 2014, Povee, 2010, Mhlanga, 2013, Pillay et al., 2012). This depicts the resilience of families who face a assortment of reactions and difficulties yet accept the child unconditionally and irrespective of the challenges that they face (Povee, 2010, Pillay et al., 2012)

The experience of the caregiver can be caused by multiple factors, each cause being unique to the individual subjectively experiencing it. It is clear therefore that a greater understanding and further explorations needs to occur into the psychosocial dynamics surrounding Down syndrome.

2.8 Caregivers and their family

When considering the experience of the caregiver, one has to take into account the other dynamics that occur within the family unit (Boyd, 2002, Pillay et al., 2012, Povee, 2010). Relationships throughout the family often suffer with one fifth of parental relationships shown to deteriorate, which affects the family as a whole (Kaufman and Uhlenberg, 1998).

Parents have been found to feel as if they lose their personal identity and are seen to merely be the carers. Due to the strain often placed on the parental relationship, steps are often necessary to attempt to preserve their wellbeing which often incorporates measures to include and support the father (Beresford et al., 2007, Povee, 2010).

In addition, most of the attention of the parent/s and or caregiver/s is often directed toward the child with 'special needs' as they require more support. This is often at the expense of the other children which may result in animosity, resentment and additional family issues (Beresford et al., 2007, Povee, 2010).

This in turn adds to the difficulties already experienced within the family unit and can either force a family apart or strengthen their sense of unity through the shared experience (Boyd, 2002, Pillay et al., 2012, Povee, 2010).

2.9 Additional resources needed when raising a child with Down syndrome

Economical demands weigh heavily on the caregiver (Thomas et al., 2011, Pillay et al., 2012), who may have to resign from their employment and forfeit their means of income in order to offer fulltime care for the child (Lam and Mackenzie, 2002). Once the child with Down syndrome has become older, they often experience health issues that require medical attention which can be costly, emotionally taxing and not always readily available in the lower socio-economic

environments of South Africa (Bross et al., 2008, Mhlanga, 2013). These children suffer an array of medical conditions (Boulet et al., 2008, Thomas et al., 2011, Pillay et al., 2012) related to the cardiovascular system (Silverman, 2007, Boulet et al., 2008). These include but are not limited to lung and respiratory difficulties such as asthma; susceptibility to influenza and pneumonia and heart defects which result in partially formed heart muscles (Silverman, 2007, Boulet et al., 2008). This results in greater expenditure by the caregivers compared to those caring for children without Down syndrome (Boulet et al., 2008). The stress of caring for the child; maintaining employment as well as trying to provide adequate health care for a child with Down syndrome is often immense (Lam and Mackenzie, 2002).

Accessing health care in South Africa for the lower socio-economic individuals is often a taxing experience (Bross et al., 2008, Mhlanga, 2013), as seen in clinical experience. This is often due to the cost of transport, long distances to travel, lengthy waiting periods, lack of healthcare professionals available, in addition to the emotional weight of caring for a sickly child (Bross et al., 2008).

2.10 Education and Down syndrome: integration into society

Other than the basic care for an individual with Down syndrome, caregivers need to be aware of individual's potential in terms of growth and educational development. Research has developed immensely in recent years in terms of education and individuals with Down syndrome (Fidler and Nadel, 2007). Educator training to equip them to handle and adequately educate an individual with Down syndrome has been one of the focused advances (Engelbrecht et al., 2001). It has been identified that individuals with Down syndrome have been in fact educated as part of mainstream schooling and have even gone on to study courses at a university level which may be attributed to the changed attitudes and skills of educators (Fidler and Nadel, 2007). This is dependent on the severity of impairment yet has been noted to be successful (McGrath et al., 2011, Fidler and Nadel, 2007). Although a child with Down syndrome will require immense family support; opportunities and will be required to complete the equivalent of mainstream school, it is not impossible (Fidler and Nadel, 2007).

One of the most influential developments regarding integration of individuals with Down syndrome into the education system, and later into society, is the characterization of the 'behavioural phenotype' (Fidler and Nadel, 2007). This term is used to classify the behavioural patterns of individuals with Down syndrome as they grow. This research, according to Fidler & Nadel (2007), has increased the understanding of particular behaviours that have been specifically associated with the syndrome in areas such as cognition; inter-personal reactions; relationships and language development. Such extensive research has been performed with regards to Down syndrome in an attempt to improve educative strategies to affect more productive outcomes with these individuals (Fidler and Nadel, 2007).

Efforts to integrate individuals with Down syndrome into society through training and educating serves to allow for more independent individuals (Baxter et al., 2000). This then reduces the stress and demands on the caregiver as the individual is far more self-sufficient (Fidler and Nadel, 2007).

As educational possibilities in individuals with Down syndrome are largely linked to their behavior (Dykens, 2007), it is vital to understand that when compared to 'average' children, individuals with Down syndrome are likely to experience "behavioral, emotional, and psychiatric problems," (Dykens, 2007, 272). These issues cause stress for the caregiver and the family and often result in difficulties in routine and everyday tasks.

2.11 Attitudes in South Africa

Stigmatization and prejudice is rife in South Africa, specifically in relation to those individuals who are not considered 'normal' (Botha et al., 2006, Lansdown, 2002, Mhlanga, 2013, Penn et al., 2010).

Culture and belief plays a large role when considering the birth of a child with a congenital diagnosis especially within the South African context (Penn et al., 2010). Causative factors are at times attributed to the behavior or lifestyle of the parents being unacceptable and religious infractions (Penn et al., 2010).

It has been found that grandmothers play a vital role in the care of children within communities as they often assume a position of power especially when considering the paternal grandmother (Penn et al., 2010, Swanson, 2007). Thus they usually have the most control over the actions and behaviours of their son, the father of the child (Penn et al., 2010). According to Penn (2010, pg 9-10), the beliefs and culture within South Africa is immense and cannot be ignored as it influences behavior and treatment when considering congenital disorders (Penn et al., 2010).

According to Lansdown (2002), some South African men are hasty in their decisions to leave their wives after the birth of a disabled child and often blame their wives for this occurrence. The Urban men that do leave are said to do so in order to escape the pressures of raising this child whilst the rural men that leave do so in an attempt to escape from the negative perceptions of the community often related to curses and failure (Lansdown, 2002, Penn et al., 2010). Therefore some of these children are raised in a single-parent household and often kept 'locked-away' from the ever judging public. This leads to a direct violation of the child's human rights including access to health care services and therapy alike (Lansdown, 2002, Constitution of the Republic of South Africa, 1996).

2.12 Support and acceptance

In stating the causes and resultant reactions to the stress experienced, it must also be noted that caregivers need to find a means to cope with the stress that they are experiencing. In this they will not only find more effective ways to deal with their own stress but also be able to assist others who are possibly experiencing the same or similar experiences.

According to Boyd (2002), two different forms of support have been documented. One of these being 'formal support' which refers to receiving help on a professional level such as through organizations or services. The other form is 'informal support' which refers to a less rigid unity of people and can include other relatives, friends, caregivers with similar experiences or even neighbours.

Support is often a stable means to cope with the difficulties that caregivers experience. It has been documented that not all caregivers in fact seek support. The characteristics of the child's impairment including physical, psychological, behavioural as well as factors such as cultural norms and beliefs play a role in the caregiver's sense of urgency when seeking support, especially from health professionals (Boyd, 2002, Mhlanga, 2013).

Positive experiences of caregivers have been recorded in addition to the negative associations of stress and high energy tasks needed to care for the child with Down syndrome. It was found that once caregivers accessed services such as schooling facilities, support groups and day care centres, they had more time for themselves and showed less signs of fatigue (Boyd, 2002, Mhlanga, 2013).

During this period, the caregivers were also able to become more accepting of the child and by association the syndrome (Boyd, 2002, Pillay et al., 2012). Thus they begin to see the progress that the individual was making rather than experiencing the intense feelings of the individual with Down syndrome being a burden. In particular, developments in social-related skills and psychomotor skills were amongst what aided the caregivers in acknowledging the positive aspects of the children. However, although growth and development of the caregivers themselves has been documented, most literature in and around the topic points towards the stressful experiences of these individuals (Lam and Mackenzie, 2002, Pillay et al., 2012).

2.13 The need for understanding

Questions need to be asked in order to gain understanding in terms of what it is like to care for a child with Down syndrome (Rajh, 2005). Investigations need to delve into factors including, what is actually the cause of the stress when raising the child? Is it one particular cause or multiple? (Rajh, 2005) Why is the cause creating a stress-response?(Van der Veek et al., 2004) Once these answers have been gathered, a better attempt may be made to prevent the experiences of stress from occurring or at least equip the individual with the coping skills to manage their experience of stress. This helps to explain the pertinent need for the study being

proposed. It not only searches for the answers but may also be used as an educative tool for individuals with the same or similar experiences.

This in turn will equip health professionals dealing with caregivers of Down syndrome individuals to better assist them in coping with the stress through providing interventions which may reduce the adverse effects of the child's behavior and or relieve their own personal stress. It will also contribute to possible review of existing relevant policy and legislation to better accommodate caregivers.

2.14 Summary

There has been a progression in terms of what society knows about Down's syndrome. This includes what the syndrome is, the impact on caregivers and their families, what factors need to be considered when raising such a child including resources, rate of development and schooling as well as how others perceive and respond to the child and caregiver. Prevalence statistics and attitudes within the South African context assist in the specificity of understanding due to the limited research conducted thus allowing for a more contextualized view.

Although there is a large sense of ignorance that surrounds the syndrome in general, advances in research have helped to educate the public and assist with understanding the diagnosis as a whole. Many discoveries have been made such as medical advances, yet there is still much to discover in terms of how the condition impacts relationships and the associated dynamics.

South Africa has its own set of dynamics that governs the perceptions of communities, this being due to a population with specific cultural beliefs. From the review it is evident that families react differently based on culture, upbringing and beliefs. This fuels their decisions as to how a child with Down syndrome should be or is treated. The community also has their role to play which affects not only the child with Down syndrome but their caregiver/s too. Thus supporting the need to research these dynamics to allow for a greater knowledge and understanding.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

In this chapter the logistical steps of the study are outlined. The design of the study is explained with a rationale. The participants are discussed in terms of the sampling technique, the size of the population and the selection criteria which allows the reader to be clear with regards to the participants that engaged in the study.

The data collection method, data collection instrument and methods of data analysis are discussed in relation to the objectives of the study. This is supplemented by the ethical and methodological considerations as well as the trustworthiness of the study. A mixed method approach with an explanatory sequential design was utilized and will be outlined in the chapter.

3.2 Research approach and design

A mixed method approach, following an explanatory sequential design (Creswell et al., 2003) was implemented. This approach was selected as it allows for data to be delved into on a deeper level and subsequent results to be 'mixed' together to supplement a more comprehensive understanding of the results and findings (Creswell et al., 2003, Creswell, 2008).

Additionally, it allows for sufficient data to be collected and analyzed through the use of both qualitative and quantitative data that would otherwise not suffice with merely the use of one method or the other (Ivankova, 2002, Johnson and Onwuegbuzie, 2004). The use of mixed methods assists in capturing the in-depth experiences and perceptions of the caregivers raising a child with Down syndrome and may potentially reduce the chance of limiting their expression (Creswell et al., 2003, Ivankova, 2002).

Mixed methods adopts a pragmatic approach and allows for both qualitative and quantitative data to be collected and analyzed sequentially, as in this study, in

order to aid in answering the proposed research problem (See *Chapter one, pg 3*) (Ivankova, 2002, Creswell et al., 2003).

Implementation, priority and integration are the three categories of importance when considering mixed method research (Creswell et al., 2003). Implementation denotes the way in which the data will be collected (Creswell et al., 2003), in this study the implementation follows a sequential pattern due to the collection and analysis of quantitative data followed by collection and analysis of qualitative data.

Priority for the study reflects which aspect (qualitative versus quantitative) is considered most valued (Creswell et al., 2003). For the purpose of this study, the first more dominant quantitative phase guides and informs the second qualitative phase. Lastly integration which encompasses the analysis, interpretation and as the title suggests assimilation of the collected findings (Creswell et al., 2003). Both the qualitative and quantitative findings were combined to produce the results in this study.

The explanatory sequential design was selected and is noted to be one of the most utilized designs when considering a mixed method approach (Creswell et al., 2003). The design facilitates the execution of two separate phases which are then interpreted individually with an overall integration of findings (Creswell et al., 2003).

Phase one incorporated a quantitative phase utilizing a descriptive survey. The aim of the descriptive survey was to identify trends in data relating to the questions posed. These categories of questions were biographical data; attitudes toward the child and participant; the challenges and coping experienced as well as the emotional experiences of the participants. This was in order to inform the second qualitative phase through identification of what further inquiry was necessary.

The data from phase one was collected and analyzed prior to phase two, a qualitative phase which was implemented. This second phase involved the use of two focus groups, an individual interview, a dyad interview and a triad interview to

obtain data. The aim of phase two was to further delve into the experiences of the caregivers driven by baseline knowledge from the first phase.

Phase two utilized an interpretive phenomenological framework (Barker et al., 2002, Smith and Osborn, 2007, van Manen, 2007) in order to gain personal, subjective and confidential information from each participant through the use of the focus groups and interviews. The schematic describes how the sequential explanatory design was utilized in the study.

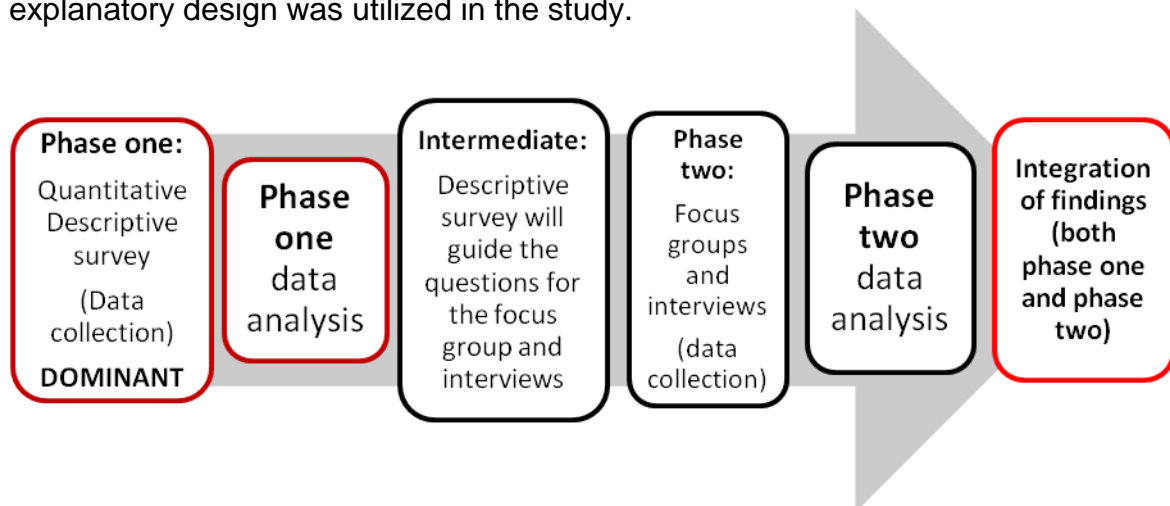


Figure 3.1 Diagrammatic representation of the research approach utilizing the Explanatory Sequential Design (Creswell et al., 2003).

In the descriptive survey, focus groups and interviews there was the opportunity for the researcher to profile the participants which assisted with later data analysis in terms of the quantitative data and participant descriptions in the qualitative data. This information was included in the information letter to the participants (See Appendices 1–6).

3.3 Phases of research

The study was conducted in two phases. The first phase was quantitative and the second was a qualitative phase thus allowing for combination of data which necessitates a mixed method approach (Creswell et al., 2003). Furthermore, phase one guided and facilitated the conduction of phase two thereby adopting a sequential explanatory design (Creswell et al., 2003) (See *Research Approach and Design*, pg 25).

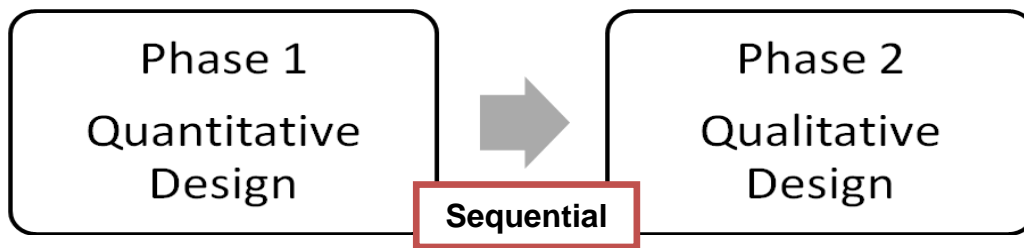


Figure 3.2 Phases of the study

3.4 Phase one: Quantitative design

A descriptive survey was utilized to gather data for the first phase of the study. The descriptive survey was compiled based on the literature reviewed. This literature aided the researcher in posing questions that allowed for data to be collected in and around the question of what it is like to raise a child with Down syndrome?

The researcher underwent a series of steps in order to create the descriptive survey. This included gaining an understanding of the rating scales available; deciding which scales were appropriate and would best suit the questions; what questions needed to be asked and the way in which each of the five questions of the descriptive survey were divided. In addition, this process allowed for greater understanding into the specificity of the emotions experienced through the participants being able to choose more than one answer in question five (See *Appendices 7-8*). These are outlined in the schematic below.

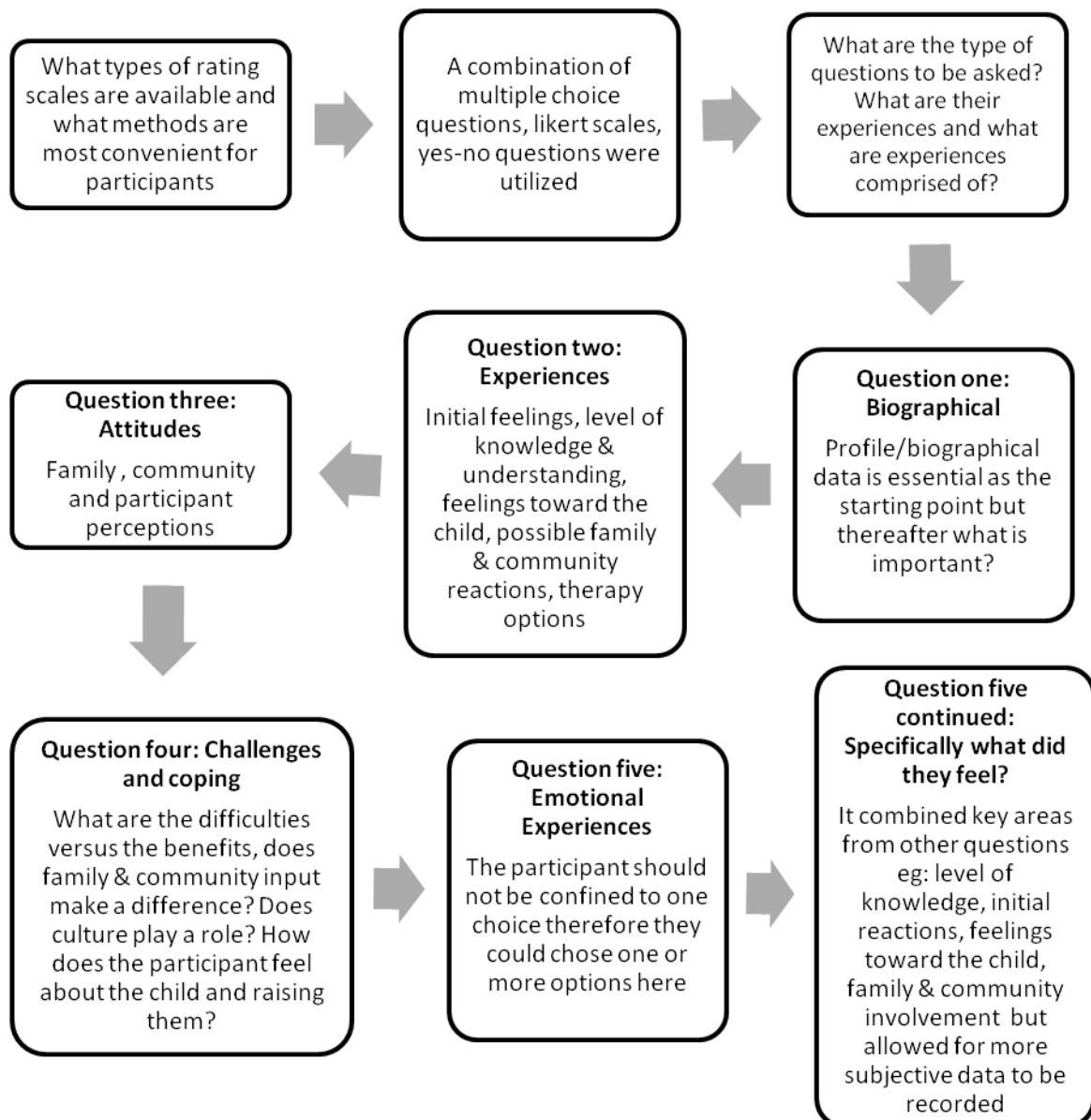


Figure 3.3 Development of the descriptive survey

3.5 Phase two: Qualitative design

Following a sequential design (Creswell et al., 2003), the second phase was enhanced by the data collected and analyzed within phase one. Based on the findings from the phase one analysis it was determined what topics required further investigation. The researcher explored the results of phase one and used emerging trends and ambiguous results to ensure that phase two delved into further detail. This was performed through the use of two focus groups, one individual interview, one dyad interview and one triad interview.

The schematic below depicts the researcher’s process in terms of what aspects needed further investigation. This included greater detail in terms of: the initial reactions of the participants; what raising a child with Down syndrome is like; what influence has the family had on the child if any and vice versa; how does the community and public respond to the child and caregiver as well as the advice or experiences could be imparted onto other caregivers to assist them when raising a child with Down syndrome.

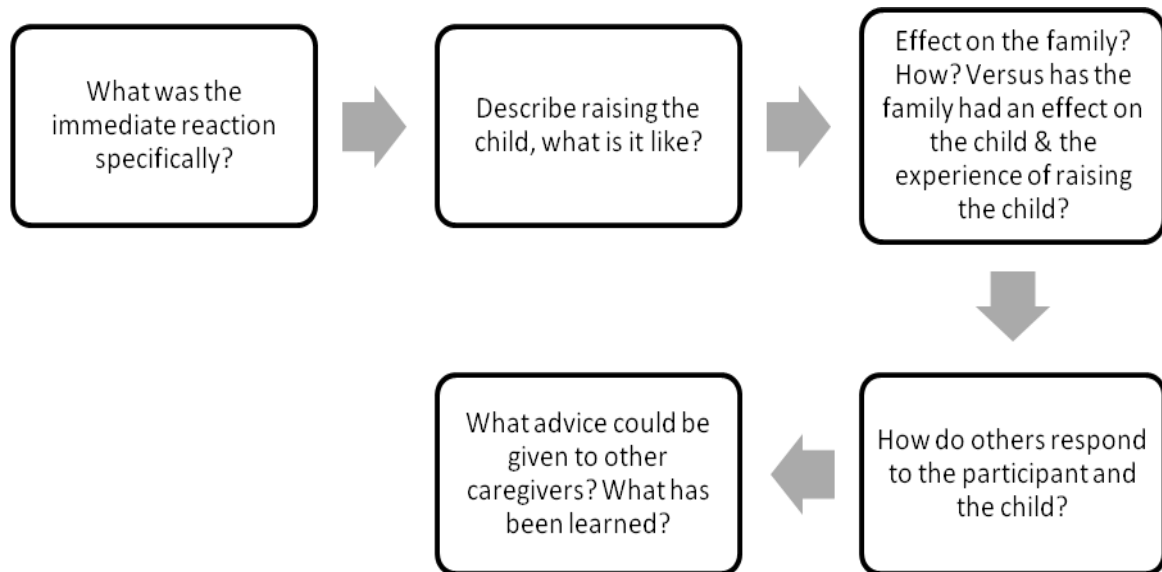


Figure 3.4 Formulation of the qualitative questions

3.6 Relationship of phase one and phase two

As per the sequential explanatory design (Creswell et al., 2003), the findings of phase one guided the data collection in phase two. Phase one allowed for further information to be drawn in phase two due to delving into emerging trends that were identified from phase one results. Aspects of the results of the descriptive survey (phase one) were extracted and served as probes or prompts within the focus groups and interviews to allow for the study to gain a greater depth of inquiry.

Phase two expanded on the questions of phase one. The schematic below depicts an example of the progression that the researcher utilized to probe or prompt further information. A question about attitudes in phase one (See Appendices 7-8) was divided into the people that may show various attitudes toward the child and

caregiver. This lead to phase two which explored the attitudes of each person through the questions asked and the probing or prompting performed (See Appendix 9).

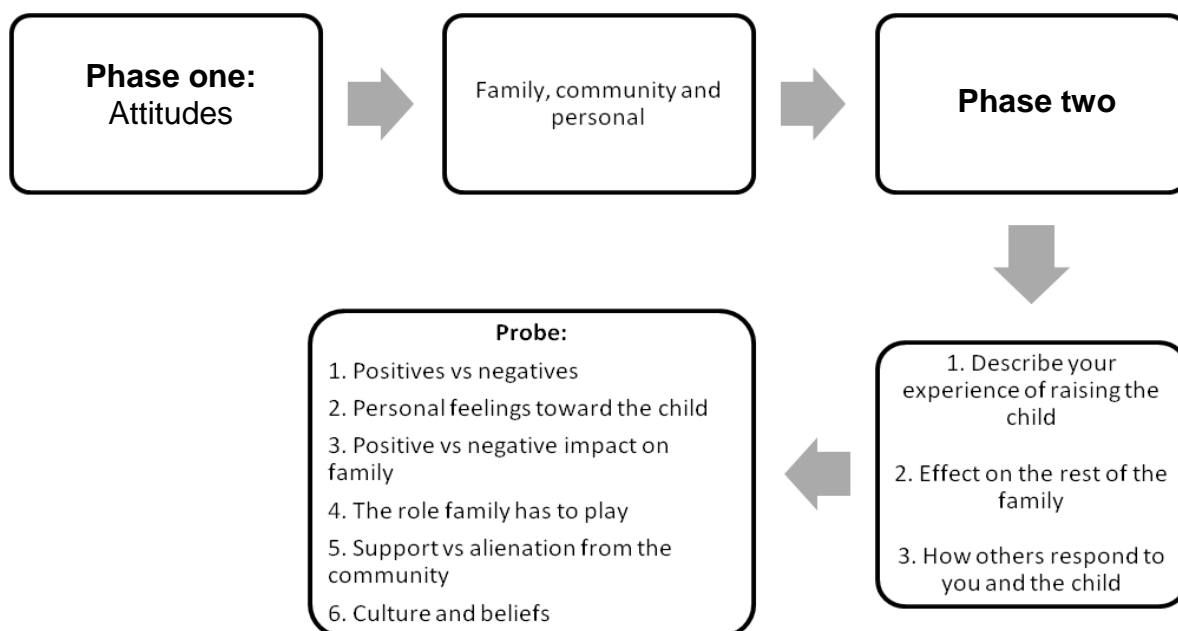


Figure 3.5 Example of how phase one data is expanded in phase two

3.7 Rationale for the choice of the research design

The use of both qualitative and quantitative data to form a mixed methods approach (Creswell et al., 2003) allowed for a more comprehensive manner in which to construct findings and subsequent analyses. It afforded the study the benefits of both approaches in a 'mixture' (Creswell et al., 2003) in order to enhance the findings. A mixed methodology allowed for additional data to be captured and analyzed in an attempt to reach saturation (Creswell et al., 2003). Phenomenology was used as a framework as although it aided in delving into the experiences of the participants and provided rich data, it served only to aid phase two and would not have assisted in gaining the preliminary quantitative data to guide the second qualitative phase.

3.8 Recruitment and selection of participants

Participants that were selected for the study were not only the parents of the children with Down syndrome. Instead participants were any individual who predominantly cares for the child such as a family member or friend of the family.

3.8.1 Population

Caregivers of children with Down syndrome who reside within KwaZulu-Natal constituted the population. As per the explanatory sequential design (Creswell et al., 2003), two phases were conducted and therefore two different population groups.

3.8.1.1 Phase one

A convenience sample of 57 participants completed the descriptive survey. The sample population was convenient in nature as the Down syndrome Association KwaZulu-Natal provided them due to the ease in which they could be contacted and engaged in the study (Schreuder et al., 2001, Doherty, 1994). It must be noted that participants who engaged in phase one were excluded from phase two. This was conducted due to the researcher attempting to gain as much data as possible from the two population groups without overlapping information or tainting the data by replicating responses (Creswell, 2008). The separation was conducted in an attempt to reach data saturation (Creswell et al., 2003, Creswell, 2008).

3.8.1.2 Phase two

A non-probability purposive sample was used to select the participants. The sample was purposive due to participants being selected for their specific relationship to the research topic (Schreuder et al., 2001) namely participants who care for a child with Down syndrome. Furthermore, the participants were selected due to their ability to answer the specific qualitative questions due to their relationship to the topic. This was to supplement the interpretive phenomenological framework through participants exploring subjective experiences (van Manen, 2007, Ivankova, 2002).

Initially eight participants were selected to participate in the first focus group, there after four participants engaged in the second focus group. An additional three interviews were conducted with a total of six participants in the form of individual, dyad, and triad.

It was necessary to conduct further interviews to probe information that would otherwise not be expressed in a group. This allowed for information saturation to

be achieved (Creswell et al., 2003). This in turn further qualifies the nature of the research design in terms of a sequential research process that allows for one phase to guide another (Creswell et al., 2003).

Since data generated through qualitative research is evolving in nature, the core questions for the semi structured interviews emerged from the two focus group themes. The population group has been represented in the schematic below.

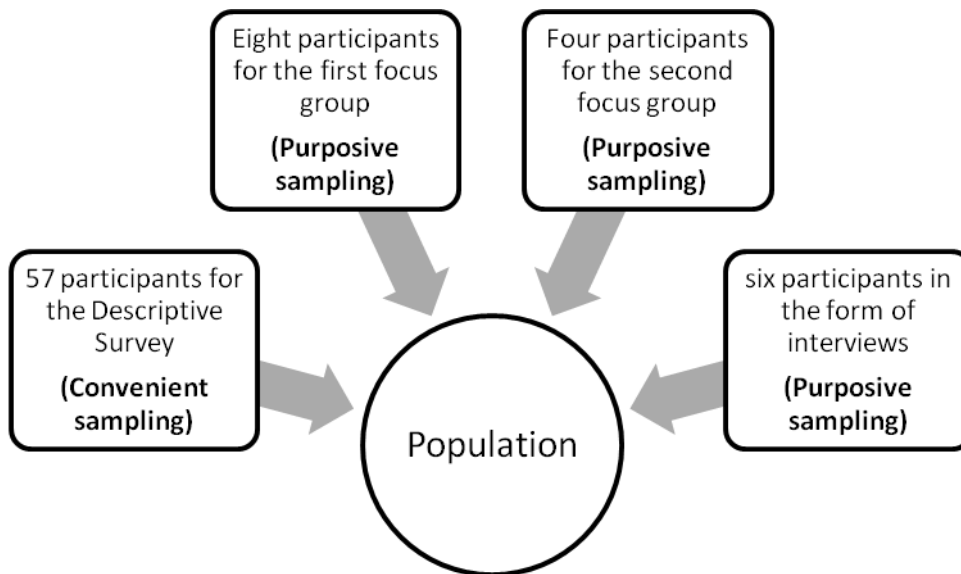


Figure 3.6 Diagrammatic representation of the Population

3.8.2 Sampling technique and size

The participants were selected from the Down syndrome Association KwaZulu-Natal database due to the wide range of membership. In addition, the Down syndrome Association KwaZulu-Natal also has an outreach program that targets outpatients in various government hospitals within KwaZulu-Natal as well as runs independent support groups. These include the genetic clinics at King Edward VIII Hospital and Prince Mshiyeni Memorial Hospital as well as regular visits to Inkosi Albert Luthuli Central Hospital, Phoenix Assessment and Therapy Centre and Mahatma Gandhi Memorial Hospital.

The researcher contacted these hospitals to obtain permission to access the clients to be included as participants in the focus groups or interviews through informing the hospital Chief Executive Officer. The researcher however was

unsuccessful in gaining the necessary permission. Thus the groups of participants for the qualitative phase of the study were accessed from the Down syndrome Association KwaZulu-Natal independent support group, via purposive sampling.

An information sheet outlining the proposed research study was presented to the Down syndrome Association KwaZulu-Natal including the inclusion criteria to assist in the selection process (*See Appendix 10*). The researcher requested that the Down syndrome Association KwaZulu-Natal inform its members about the descriptive survey and focus groups electronically or via postage (with their newsletters) to inquire as to whether any member was interested in participating in the research. In the same manner, the researcher requested that members from the outreach program be contacted and informed of the study as well. In this way, confidentiality of the members was maintained.

3.8.2.1 Phase one

The descriptive survey was electronically forwarded to the Down syndrome Association KwaZulu-Natal members together with their newsletter (*See Appendices 7 & 11*). The researcher also arranged to distribute the descriptive surveys to the outreach support groups by attending the groups to assist with diversity of the sample. The final sample size was 57 participants. The exact numbers of participants contacted is unknown as many e-mails were sent by the association on behalf of the researcher as well as members informing other members and thus the exact numbers were not recordable. Five participants were selected for the pilot study which was conducted prior to the data collection process (*See Pilot study, pg 40*). The process of phase one sampling is depicted in the schematic below.

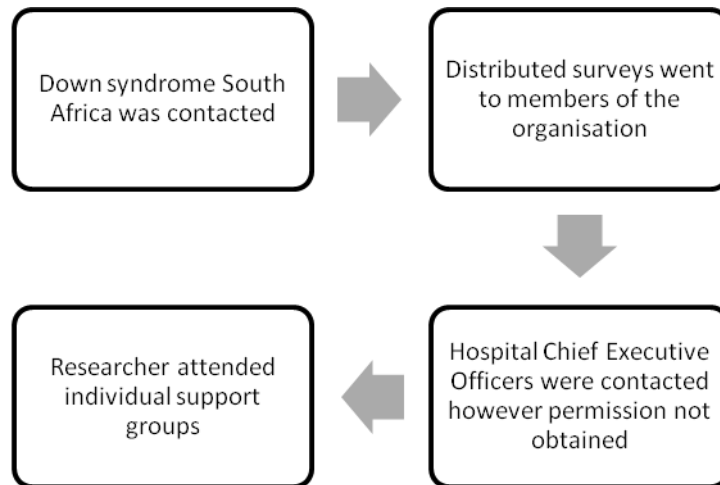


Figure 3.7 Sampling technique: Phase one

3.8.2.2 Phase 2

Eighteen participants via purposive sampling were selected by the association and the researcher. Eight participants were selected for the first and four for the second focus group. Four participants were selected for the pilot study which was conducted prior to the data collection process (*See Pilot study, pg 40*).

These potential participants were then telephonically contacted by the researcher whereby the proposed research study was explained and their subsequent interest in participating and fulfillment of the inclusion criteria was utilized to decide whether the individual was to be included. In addition the details and purpose of the focus groups were discussed.

Confidentiality of the participant and of the information obtained through appropriate storage and disposal of the data after transcription was explained. The participants' right to withdraw at any point without any consequences was also explained.

The participants were contacted a month prior to data collection, and then notified a week prior to the set date. Lastly the participants were reminded a day prior to the research focus group dates and interviews, to assist in preparation of the participants.

3.8.3 Participant inclusion criteria

Phase one:

The following criteria was utilized when selecting participants

- I. Members of the Down syndrome Association KwaZulu-Natal.
- II. Individuals that attend the genetic clinics that the Down syndrome Association KwaZulu-Natal includes in their outreach program namely: King Edward Home Program Clinic and Prince Mshiyeni Home Program.
- III. Individuals that attend the hospitals that the Down syndrome Association KwaZulu-Natal includes in their outreach program namely: Inkosi Albert Luthuli Central Hospital, Phoenix Assessment and Therapy Centre, Mahatma Memorial Gandhi Hospital.
- IV. The child that the caregivers care for had to have a formal diagnosis of Down syndrome.
- V. All participants needed to reside within KwaZulu-Natal.
- VI. All participants needed to communicate in either English or isiZulu as their home language or be bilingual in these languages.

Phase two:

The criteria outlined for phase one including the following additional criteria was used for this phase

- I. The participants must not have participated in the descriptive survey of phase one.
- II. All the Caregivers have to be or have cared for the child with Down syndrome for at least five years to ensure that they have enough subjective experience in order to report and offer their experiences.
- III. The child with Down syndrome is to be within the age of five to eleven.

The age group of the children with Down syndrome was chosen as this is the time when they begin to integrate with others by attending school and begin to gain some independence (Erikson, 2002, Buckley and Sacks, 2001). In addition, this excludes children who are currently going through or have gone through puberty which may create further dynamics to the caregiver-child relationship.

The schematics below depict the inclusion criteria for phase one and phase two including the differences.

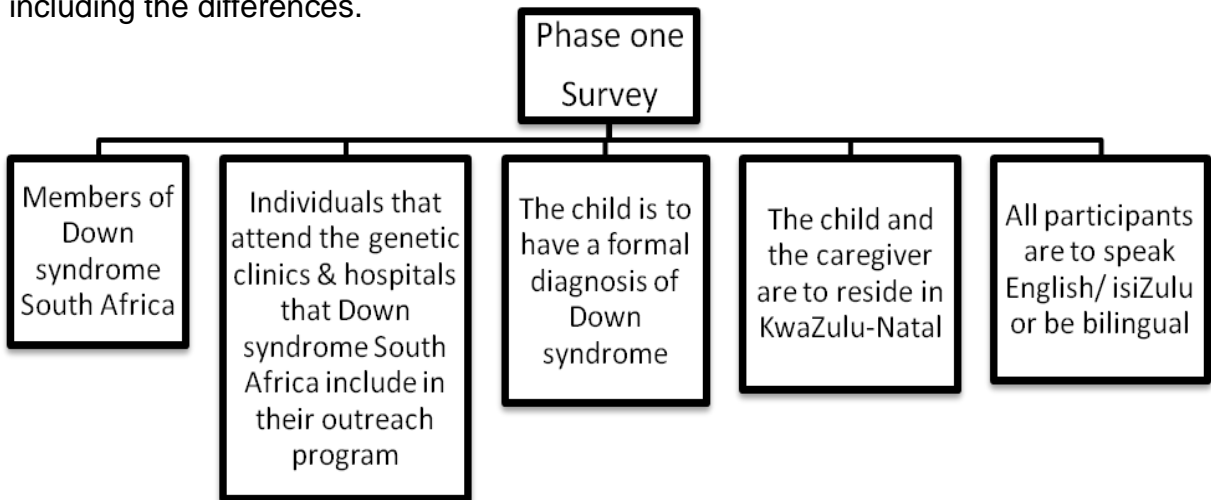


Figure 3.8 Diagrammatic representation of the inclusion criteria phase one

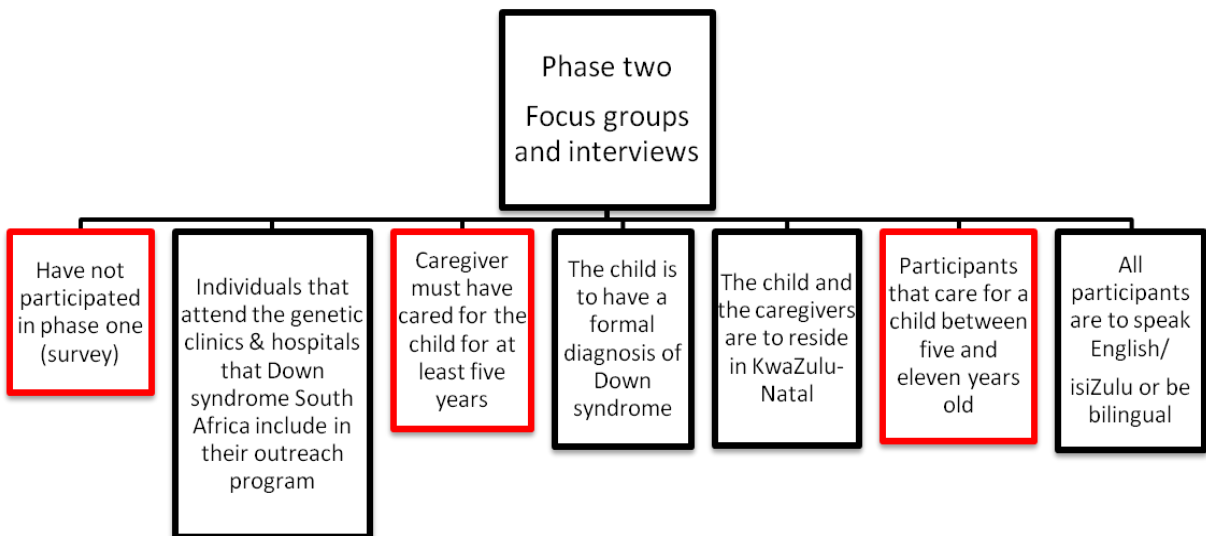


Figure 3.9 Diagrammatic representation of the inclusion criteria phase two

Note: The boxes highlighted in red show the additional criteria that are not seen in phase one

3.9 Data collection instruments

The instruments utilized in the study are described below, namely a descriptive survey, focus groups and interviews.

3.9.1 Phase one: Descriptive Survey (See Appendices 7, 8, 11)

The quantitative phase initiated the data collection process with the aim to gather enough relevant data to guide the second phase, as per the sequential design (See *Research Approach and Design*, pg 25), to allow for the results to reflect a high level of rigor (Creswell et al., 2003).

The descriptive survey was created based on literature reviewed in terms of what types of surveys are effective, what types of rating scales are comprehensible for the participants and which scales would be appropriate for the questions being posed. The aim of the survey was to explore what the perceived experiences are when raising a child with Down syndrome. Therefore research was conducted surrounding what questions need to be asked in order to gain insights into the experiences. The survey was divided into five sections that addressed areas of the participants' experiences. The first section involved biographical data which allowed for participant profiling and acquisition of prevalence factors (such as age, gender, type of Down syndrome). The other sections involved attitudes of the participant, community and family; challenges and coping; experiences of caring for the child and emotional experiences (See *Appendices 7 & 11; Figure 3.3*, pg 29). The last section allowed for participants to select more than one answer which enhanced their ability to express themselves. The last section, due to the specificity of emotional experiences assisted in guiding the questions in phase two.

Furthermore, the descriptive survey was structured through the use of various sections that delved into the areas relating to the research question. The research question highlighted the aspects that required further exploration, namely, 'perceptions', 'experiences' and 'coping strategies' of the caregivers (See *Research Question*, pg 4). The table below represents the relationship between the research question and the questions asked in the descriptive survey.

Table 3.1 Representation of the research question in relation to the descriptive survey

Research question area:	Category in the descriptive survey	Questions in the descriptive survey
Perceptions	Attitudes	Question three (3.1 – 3.5)
	Emotional Experiences	Question five (5.1 – 5.15)
Experiences	Experiences	Question two (2.1- 2.35)
	Biographical (e.g.: the amount of years caring for the child)	Question one (1.1 – 1.10)
	Challenges and coping	Question four (4.1 – 4.15)
	Emotional Experiences	Question five (5.1 – 5.15)
Coping strategies	Challenges and coping	Question four (4.1 – 4.15)

3.9.2 Phase two: Focus groups and interview schedule (See Appendices 12-13)

Once phase one data was analyzed, the researcher was able to identify the areas that needed further exploration in phase two (Creswell et al., 2003).

The instrument utilized was the focus groups and interviews, however due to the evolving nature of focus groups and interviews, the wording of the questions changed marginally. In addition, probing questions were utilized to further delve into the data being collected (See Figure 3.5, pg 31).

As seen in phase one, the questions were related to the research question which highlighted 'perceptions', 'experiences' and 'coping strategies'. Within phase two, the questions were also linked to the research question to ensure that the results answered the posed research question.

Table 3.2 Representation of the research question in relation to the focus groups and interviews

Research question area:	Focus groups and research question	Relevant probing questions
Perceptions	Question 3: Impact on the family	Positive versus negative Reaction of siblings and/ spouse
	Question 4: How others respond to you and the child	Community attitudes Acceptance Barriers and limitations Cultural influence
Experiences	Question 1: Immediate reaction	Self blame/ guilt
		Knowledge versus ignorance
		Sadness versus acceptance
	Question 2: The experience of raising the child	Positives versus negatives
		Child's level of dependence
		Feelings of love toward the child
	Positive versus negative impact on the family	
Coping strategies	Question 2: The experience of raising the child	Support structures
	Question 5: Advice to other caregivers	Coping mechanisms Overcoming stress

3.10 Pilot Study

Prior to the implementation of the survey, the focus groups and interviews, a pilot study was conducted by the researcher. This served to identify any problems with the questions to be posed and the process of running the group by the researcher. It allowed the researcher to make necessary adjustments to the survey and focus group schedules prior to the official survey, focus groups and interviews.

3.10.1 Piloting the descriptive survey

The survey was distributed to five caregivers of children with Down syndrome selected from the Down syndrome Association KwaZulu-Natal data base. The

feedback resulted in identification of ambiguous questions as well as difficulties that could be experienced due to double negatives, especially for first language isiZulu speakers. The information assisted in adjusting the questions so that they were easier to understand and the descriptive survey was more comprehensible. The adjusted surveys were sent back to the original five participants who did not report any further difficulties.

3.10.2 Piloting the focus groups and interview questions

Four caregivers of children with Down syndrome were selected from the Down syndrome Association KwaZulu-Natal data base. They did not meet the inclusion criteria in terms of raising a child within the ages of five to eleven years; however, the other inclusion criteria were met. This was as a result of decreased response rates and the need to utilize participants that meet all the criteria for phase two. Feedback was received in terms of improving the prompting questions which was performed prior to the initiation of phase two.

3.11 Data Collection Method

The data collection method is described below including the use of the descriptive survey, focus groups and interviews.

3.11.1 Phase one: Descriptive survey

The Down syndrome Association KwaZulu-Natal was contacted by the researcher (*See Appendix 10*). Multiple coded surveys (both in English and isiZulu) were distributed with a total completion of 57 surveys (*See Appendices 7,8,11*). Surveys were given to members of the Down syndrome Association KwaZulu-Natal that had shown interest in participating.

The researcher utilized the assistance of a co-facilitator who was fluent in isiZulu and English on site at the support groups. This was to ensure that participants understood the questions in the descriptive surveys (whether the descriptive surveys were in English and isiZulu) and could request clarity on items to ensure successful completion of the descriptive survey. This also ensured that any participants that were functionally illiterate were also able to complete the survey by having it read to them in either English or isiZulu.

The participants also received a description of the study; the purpose and an explanation about the descriptive survey with the estimated time period of 15 minutes to complete the descriptive survey (*See Appendices 1-2*).

After a period of two months the researcher collated all the surveys that had been sent electronically.

3.11.2 Phase two: Focus groups and interviews

Participants that were selected for the two focus groups spoke the same language, isiZulu. That assisted with the flow of information that may have been hampered by any language barriers or delays for interpretation. It also ensured that participants were each able to contribute to the group without any difficulties caused by language.

The focus groups spanned approximately one hour. Eight participants were selected for the first and four for the second group. The participants met at an accessible venue which was organized and provided by the researcher.

The content of the session was recorded using an audio/digital recorder. The researcher asked the questions in English and the co-facilitator repeated the isiZulu translation. The participants spoke in isiZulu as their first language and a co-facilitator fluent in isiZulu and English was included in the focus group sessions. The co-facilitator and researcher wrote down participant reactions in relation to the question being asked (by noting the question and reaction given by each participant). Thereafter the co-facilitator explained the response of each participant (in summary) to ensure the researcher could ask any follow-up questions.

This was performed in order to ensure that there were no misunderstandings related to language barriers and the co-facilitator was able to assist with the data capturing process such as recording of non-verbal cues and taking additional notes. It is notable that the co-facilitator used was an Occupational therapist who was familiar with the study and the process.

Individual, dyad and triad interviews were also conducted with a total of six participants who were digitally audio-recorded. Interviews were held at venues that were convenient for the participants. Where necessary, a co-facilitator fluent in isiZulu and English was once again utilized.

3.12 Data Analysis

The analysis of data is explored below in terms of phase one, statistical analysis and phase two, thematic analysis.

3.12.1 Phase one: Descriptive Survey

The statistician was contacted and the descriptive survey was coded during the piloting phase of the study. In this way, each question was allocated a number to be used to easily identify the option chosen by the participants and analyze whether there were trends forming in the data. Coding was conducted utilizing Microsoft Excel (2007) whereby the responses to each question were allocated a numerical value (*See Appendix 8*). This was to allow for easier descriptive analysis once the data analysis phase was reached.

Once the data was collected, the researcher again contacted a statistician who assisted with data analysis. The results were analyzed utilizing the Statistical Package for Social Scientists (SPSS) (version 21) and Microsoft Excel (2007) to obtain frequencies and tables.

SPSS (version 21) allowed the statistician to perform tests on the coded data and produce multiple tables and frequencies. This represented the percentage values of each question in the descriptive survey. The results depicted in the tables represented chi-squares, p-values, and the significance of the data results. The tables and frequencies were then converted to graphs within Excel. The results were then represented graphically and in tabular form within Chapter four, the results.

3.12.2 Phase two: Focus groups and interviews

Data was recorded using an audio/digital recorder to allow for repeated replay in order for accurate transcription by the researcher. Recorded data was transcribed

verbatim. Notes were made on any vocal intonations indicating emotions such as anger, frustration or crying to allow for the phenomenological aspect of the study to be realized.

The recorded data was divided into three processes namely 'reducing data', 'displaying data' and 'drawing and verifying conclusions' (Miles and Huberman, 1994).

A. Process one: Reduction of data

This process summarizes the data collected which allows for relevant patterns to emerge. The researcher then begins to code or 'label' the data based on the reviewed information. (Miles and Huberman, 1994).

B. Process two: Display of data

Data is then associated, highlighting the emerging relationships between information. This is in order to view the interrelatedness of the data that has already been reduced within the first process (Miles and Huberman, 1994). The use of a tabular report in the software package Nvivo (version 10) (See *Appendix 14*) allowed for the data to be displayed.

C. Process three: Drawing and verifying conclusions

The researcher now begins to identify patterns and links between the collected information. This allows for the data to be analyzed and interpreted based on what information is highlighted in the three processes (Miles and Huberman, 1994).

Thereafter, the researcher went through a process of thematic analysis. Thematic analysis allows for patterns to emerge from data collected and thus subsequent themes to be defined (Braun and Clarke, 2006).

Transcribed data from two focus groups and three interviews was imported into the software package Nvivo (version 10). Utilizing this program, **nodes** (also referred to as codes) were created based on the data collected. These nodes act

as folders in which relevant direct quotes may be stored for later analyses and correlations. This links to process of reducing data (Miles and Huberman, 1994).

Thereafter **child nodes** (also referred to as categories) were created as extensions of the nodes in order to further explore captured data. The child nodes also allowed for relevant quotes to be stored as with the node. This was achieved through the use of in-vivo coding, descriptive coding and emotion coding (Kruckenberg, 2012, Saldaña, 2009, Miles and Huberman, 1994).

In vivo coding involved the researcher using the content of the information gathered to 'label' or name it within a code (Kruckenberg, 2012). They are usually seen as direct quotes as they are taken straight from the transcribed data (Kruckenberg, 2012, Saldaña, 2009, Miles and Huberman, 1994). Descriptive coding creates a summary of the data and outlines the points of importance (Kruckenberg, 2012, Saldaña, 2009, Miles and Huberman, 1994). Emotion coding allows for data to be grouped based on one or more emotions that emerged from the data such as anger or happiness (Saldaña, 2009).

Once the data had been allocated to **nodes and child nodes**, a tabular report depicting the interrelatedness (*See Appendix 14*) as part of the Nvivo software package (version 10) was created. This allowed for multiple pieces of information to be compared and contrasted. It also allowed for the researcher to view the findings in a tabular manner and start identifying concrete patterns. This links to process two in which data is displayed. (Miles and Huberman, 1994).

Lastly, **themes** are derived from the nodes, child nodes and tabular report. These are the patterns that emerge from the data that can be placed together and 'labeled' (Braun and Clarke, 2006). These themes link to process three in which the researcher draws and verifies conclusions (Miles and Huberman, 1994).

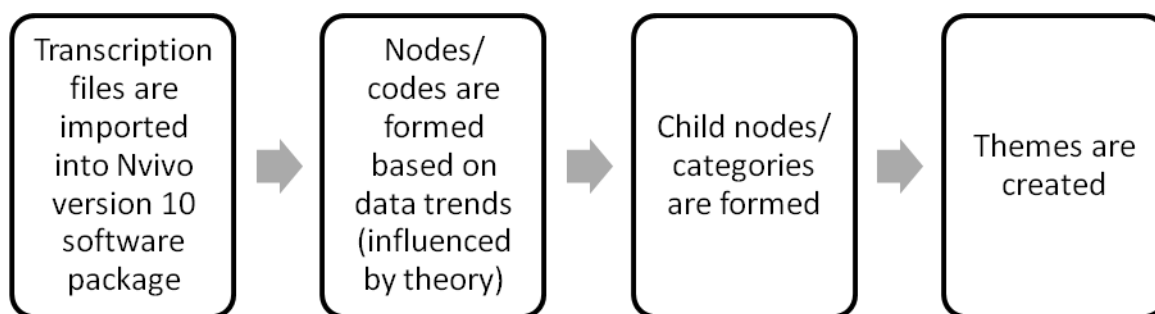


Figure 3.10 Data analysis using Nvivo (version 10) software package

Themes that emerged were based on a thematic inductive approach to analysis (Braun and Clarke, 2006). This is considered a ‘bottom-up’ approach as the themes that emerge are related to the data that is obtained and not driven by the researcher’s theoretical influences. Thus the approach favours results that are guided by the data and allow information to emerge with the formation of new ideas rather than the researcher’s preconceived ideas (Braun and Clarke, 2006, Chan et al., 2013). Thus the use of bracketing or removing the researcher’s prejudice or beliefs allows for the phenomenon experienced by the participants to emerge untainted (Chan et al., 2013).

The researcher, with the use of Nvivo (version 10) created nodes based on the questions asked at the focus groups and three interviews, which were influenced by the literature. The analysis of the qualitative data using the above stated approaches allowed for in-depth subjective experiences to be conveyed, within the interpretive phenomenological framework (van Manen, 2007).

3.13 Quality Inference

Quality Inference relates to drawing conclusions from the research data (Teddlie and Tashakkori, 2009). It begins during data collection whereby the researcher begins to formulate ideas about the data which is transported and developed through the analysis process (Teddlie and Tashakkori, 2009). Quality inference speaks to both the quantitative phase in terms of ‘validity’ (‘internal’, ‘statistical and ‘conclusion validity’); ‘reliability’ and ‘generalisability’ and the qualitative phase in terms of ‘credibility’; ‘trustworthiness’; ‘reliability’ and ‘transferability’ (Teddlie and Tashakkori, 2009, Graneheim and Lundman, 2004).

3.13.1 Credibility

Within qualitative research this refers to the key elements of the study and how the researcher collected data and subsequently analyzed the data to reflect those focal points of the research (Graneheim and Lundman, 2004). Credibility can be enhanced through selecting participants that have an array of experiences that may contribute to the enrichment of the data collected (Graneheim and Lundman, 2004). Within the study, participants were selected from various socio-economic and cultural backgrounds as well as age ranges to allow for the diversity to be explored.

Data collection and the instrument plays a large role in credibility (Graneheim and Lundman, 2004). Although the amount of data to collect has no concrete parameters, as long as the data is sufficient to address the research question (See *Chapter one, pg 4*) it maintains a level of credibility (Graneheim and Lundman, 2004). The sequential two phases of the study (Creswell et al., 2003) allowed for data to be collected in two beneficial ways and ensured that phase one guided phase two and added to the rigor of the study.

The production of themes and relevance of information used adds to credibility (Graneheim and Lundman, 2004, Braun and Clarke, 2006). Systematically ensuring that no information has been excluded and instead has contributed to the overall findings, assists with credibility (Graneheim and Lundman, 2004). Various coding processes such as in vivo coding, descriptive coding (Kruckenberg, 2012, Miles and Huberman, 1994, Saldaña, 2009) and emotion coding (Saldaña, 2009) were utilized to ensure rigor. Within this study, the software package, Nvivo (version 10) assisted with tabular representation of findings, nodes and child nodes and therefore allowed for data to be analyzed in a comprehensive manner (See *Appendix 14*).

3.13.2 Reliability & Trustworthiness

Reliability within the research context mainly refers to accuracy with regards to the data collection instrument (Ivankova, 2002).

3.13.3 Accuracy

The accuracy of the study is described in terms of the language use, English and isiZulu as well as the accuracy of the tool utilized for both phases.

3.13.3.1 Accuracy of language for phase one and phase two

The survey and focus group questions were translated into isiZulu by utilizing a translator, who was trained in this process (*See Appendix 15*). The documentation was cross-checked to ensure accuracy.

The use of an English/isiZulu interpreter was used at the survey, focus group and interview data collection stages to ensure that the participants understood the questions as well as how to complete the survey. The use of an English/isiZulu interpreter within the focus groups and interviews contributed towards accuracy of information collected and true to the subjective experiences of the participants (Jacobs et al., 2001).

The interpreter/co-facilitator utilized was an Occupational therapist to ensure greater reliability in translation due to the fact that they were familiar with the process involved. The interpreter/co-facilitator also ensured that non-verbal cues and additional information was recorded. In addition, where applicable, the recorded and transcribed data was translated into English and then cross checked by translating the English back into isiZulu and verified to ensure accuracy of the transcription.

The interpreter/co-facilitator was briefed initially by the researcher with regards to the process and the accurate conduction of the research process. It was also requested that she translated as accurately as possible from isiZulu to English and vice versa to prevent any information being misinterpreted (Cambridge, 2004).

3.13.3.2 Accuracy of the tools

The concept of 'transparency' (Teddle and Tashakkori, 2009) was utilized to contribute to the 'quality' and 'credibility' of the study. It refers to the transparency of information that is shared by the researcher with the participants involved, thereby allowing them to receive in-depth explanations of all aspects of the study,

why and how participants were selected, data analysis and how inferences or conclusions were drawn (Teddlie and Tashakkori, 2009).

3.13.3.2.1 Phase one

During data analysis of phase one (quantitative), it was found that participants answered similarly phrased questions in the same manner. Throughout the descriptive survey, questions were asked in different ways with the same or similar meaning. Majority of participants were found to answer 'yes' to one question then they would answer 'yes' to the equivalent answer later in the survey. This was a process put in place by the statistician and analyzed accordingly. This process showed that the participants understood the survey and how to complete it which adds to the accuracy.

3.13.3.2.2 Phase two:

Due to the sequential explanatory design (Creswell et al., 2003) phase one guided phase two ensuring that questions asked were relevant and understandable. This was enhanced through the use of a pilot study (*See Pilot study, pg 40*).

3.13.3.3 Accuracy with participants

Once the data was transcribed and analyzed, the themes and sub-themes that emerge were organized by the researcher. Thereafter four participants were contacted electronically and/or telephonically to ascertain their opinions of the themes which aids in verifying the accuracy and validity of the themes that have emerged. This is known as member checking and is considered a strong method of determining the trustworthiness of the conclusions drawn by the researcher (Teddlie and Tashakkori, 2009). The participants that were contacted verified that the themes that emerged were relevant.

3.14 Ethical Considerations

The ethical considerations explored encompass: the participants' autonomy; their sharing of information; consent of participants; the research process; confidentiality; storage and access of the research data.

3.14.1 Autonomy

The participants were informed by the researcher that they may withdraw at any phase of the data gathering process, and in doing so it would in no way jeopardize them. Through the information provided by the Down syndrome Association KwaZulu-Natal, members were able to decide whether they wished to participate in the study or not.

3.14.2 Divulging of subjective information

Due to the sensitive nature of the questions in the focus groups and interviews as well as the emotive content that arose, the researcher emphasized that should any participant feel distressed they were able to take a break from the focus group, choose to stop speaking until they feel comfortable again or withdraw from the study. The researcher also emphasized that all participants should only share what they are comfortable sharing and not feel forced to place themselves in unnecessary emotional states. The researcher was available to provide onsite debriefing (in private) for any participant who required this; however, no participants needed additional support. The researcher gave all the participants options of counselors/psychologists within the KwaZulu-Natal region, should they require additional support after the focus groups and interviews had ceased (See *Appendices 3, 4 & 16, 17*).

3.14.3 Consent

- I. Gatekeeper permission was applied for by the researcher. The Down syndrome Association KwaZulu-Natal was asked to provide preliminary consent (should they agree to assist with the study) to allow for the researcher to apply for ethical clearance (*See Appendix 18*).
- II. Ethical clearance was applied for via the UKZN Research, Ethics and Higher Degrees Committee.
- III. Thereafter, official consent was obtained from The Down syndrome Association KwaZulu-Natal (*See Appendix 10*).
- IV. Once the list of participants that were chosen to participate was identified through The Down syndrome Association KwaZulu-Natal, their consent was also obtained (*See Appendices 16-17*).

3.14.4 Research Process

After The Down syndrome Association KwaZulu-Natal obtained consent and provided participants; an information sheet clearly setting out the purpose and method of research including what is expected of the participants was made available to each participant and they were provided with the opportunity to question any aspect that is not clear to them (See Appendices 1-4).

The researcher provided all participants involved in the focus groups and interviews with a consent letter that was separate to the information sheet and that they were required to sign prior to data collection and the commencement of the study. Each participant received a copy of the consent form. The letter was provided in both English and isiZulu to ensure easy and accurate understanding, (See Appendices 16-17). At the end of the focus groups a brief profiling sheet was handed out and the purpose of it was explained (See Appendices 5-6). The research process has been represented in the schematic below.

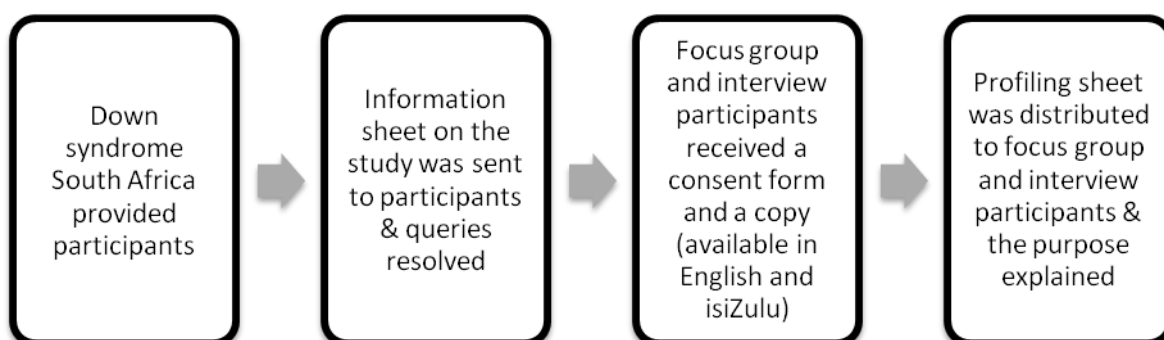


Figure 3.11 Diagrammatic representation of the process

3.14.5 Confidentiality

Confidentiality in terms of participants; research; co-facilitator and interpreter are discussed below. This included storage of important documents.

3.14.5.1 Anonymity of participants

The researcher only contacted possible participants once The Down syndrome Association KwaZulu-Natal had given their consent to have their contact details given to the researcher. As the association was the link between the researcher and the formulation of this study, it was of utmost importance that confidentiality of

the individuals was maintained and that they played an active role in the study with its subsequent results.

Participants remained anonymous during the survey and confidentiality was maintained in written documents for participants of the focus groups and interviews, in which a coded name to allow for identification only by the researcher was allocated. The researcher did not at anytime disclose any of the personal details of the participants involved. This included the recordings during data collection, the analysis process, and formulation of the findings as well as any data after the study had been completed.

3.14.5.2 Storage of important information and documents

All information was archived. Recordings and typed information was kept on computer with password access whilst written notes were kept in the researcher's safe to prevent exposure of confidential information to those not involved in the study. Data will be destroyed after a period of five years. The researcher also signed a confidentiality agreement (*See Appendix 19*).

3.14.5.3 Confidentiality relating to the Researcher and Co-facilitator/Interpreter

A confidentiality agreement was signed by the researcher and the interpreter/co-facilitators to ensure that any information divulged during the completion of the descriptive survey, focus groups and interviews is kept confidential and not disclosed outside of the research environment (*See Appendix 19-20*).

3.14.6 Access to research study results

The participants were given the option to receive a copy of the findings of the study. On the consent forms was the option for the participants to indicate whether they wish to receive a copy and the mode (such as postage or electronic copies).

3.14.7 Beneficence

The principle of beneficence is to endorse good and be of benefit to those involved (Murphey, 1993). It also encompasses increasing benefit to society (Israel and Hay, 2006). Through engagement in the study, participants are promoting the

gathering of new data with will have a positive result on KwaZulu-Natal research (Israel and Hay, 2006). As the participants agreed that there is a lack of information surrounding Down syndrome in KwaZulu-Natal, their input will aid other caregivers through development of new results. In this way, accompanied by participants not being at risk through engaging in the study, they are aiding the researcher in acquiring new literature and thus promoting a good outcome (Murphey, 1993, Israel and Hay, 2006).

13.14.8 Nonmaleficence

This encompasses the principle of not inflicting harm (Gillon, 1985) or reducing the chance of harm or discomfort for the participant (Israel and Hay, 2006). It was explained to the participants that they were able to withdraw from the study without consequence at any point should they feel it is necessary. Participants were allowed to remove themselves from the interviews and focus groups at any stage should they require time to collect themselves. In addition, participants did not have to answer any questions that they found distressing or with which they were uncomfortable.

13.14.9 Justice

This relates to fair and equal treatment of those involved in the study free from exploitation (Israel and Hay, 2006). The participants were treated equally by the researcher. All aspects of engagement in the study by participants followed an autonomous standpoint whereby participants chose to participate and were in no way coerced. All participants in the quantitative phase remained anonymous and all participants in the qualitative phase received pseudonyms. All treatment was equal without favouritism or mistreatment.

13.14.10 Benefit and risk

Risks are encountered in research, although sometimes minimal, they are larger than what one would meet on a daily basis (Israel and Hay, 2006). Therefore it is vital that the benefits balance or outweigh the risk (Israel and Hay, 2006). In terms of the study there is the risk that participants may misrepresent perceptions of others. This is due to participants divulging their subjective perceptions of how the community, their partners, their children and other parties feel. There is also the

risk that participants may become distressed as a result of speaking openly about sensitive topics. However, the benefit of obtaining new data results is a large benefit. In terms of misrepresentation, the conduction of multiple interviews and focus groups allowed for a consensus to be obtained and ensured that any findings reported was as a result of numerous inputs made. The researcher ensured that the participants understood that they were in no way compelled to answer sensitive questions and were debriefed at the end of each session and gave each of them a referral sheet for counseling.

13.14.11 Referral

See Conceptual Framework: Psychodynamic Perspective, pg 7 and Divulging of subjective information, pg 47

3.15 Summary

As represented in this chapter, the main areas of importance surrounded acquisition of participants in a safe and ethical manner, data collection that was accurate, within the limits of the participants' rights, promoting beneficence, nonmaleficence and justice as well as maintaining reliability, trustworthiness and a high level of ethical standards.

The aims and objectives of the study guided the process to facilitate acquisition of accurate and meaningful data. The methods described ensured that appropriate participants were selected; they met the criteria depicted in the chapter and ensured that they engaged in the study utilizing their autonomy.

CHAPTER FOUR

RESULTS

4.1 Introduction

Data from phase one and two will be reported in this chapter. Phase one was analyzed statistically and is represented graphically and in tabular form. Phase two was analyzed using qualitative thematic analysis with the use of various coding processes (See *Chapter three, Data analysis, pg 43*). The two phases were analyzed as per the mixed method approach (Creswell et al., 2003). The results of both analyses are presented within this chapter and merges with the data presented in the subsequent chapter (See *Chapter five, pg 90*).

4.2 Phase one: Demographics

In terms of the quantitative data derived from the descriptive survey, the following demographics are highlighted.

Of the 57 participants, majority (71.9%) were female. 47.4% were African, 40.4% Caucasian, 7% Coloured and 5.3% were found to be of the Indian race. The participants were predominantly English speakers (54.4%).

The percentage for gender of the children cared for showed 49.1% were male and 50.9% female. 38.6% of the participants cared for a child under the age of five years followed by 26.3% caring for children between the ages of five-ten years. 89.5% of the children were diagnosed with Trisomy 21 whilst 7% percent of the participants indicated that they were unaware of the child's type of Down syndrome.

94.7% of the participants indicated that they were the biological parent with 1.8% being a guardian, family member or other.

52.6% of the participants lived in a city or town, 28.1% living in townships 15.8% living in informal settlements and 3.5% living in other settings.

4.3 Phase one: Findings

The following results collected from the descriptive surveys have been analyzed and represented graphically to assist with easier representation of the captured data.

As the descriptive survey included options to indicate emotions experienced at various life events, combinations of the various emotions have been represented when they occurred frequently. This is in addition to individually represented emotions that were experienced. Thus only combinations of two or more feelings that appeared five or more times are listed separately. Emotions listed in combinations that occurred less than five times were added to the individual emotions. Therefore the sum of frequencies usually exceeded 57 (the number of participants). The combinations have been shown on the graphs.

4.3.1 Graphical Representation

The following graphs explore:

- I. Participants' initial reaction to discovering that the child has Down syndrome
- II. Participants' initial feelings towards the child
- III. Participants' level of knowledge or understanding of Down syndrome
- IV. Participants' knowledge of how Down syndrome occurs
- V. Participants' knowledge of therapy options initially versus currently
- VI. Participants' reactions to telling their families and communities
- VII. Participants' possible difficulties with family members
- VIII. Relationship of positive and negative responses when raising a child with Down syndrome
- IX. Participants' experience of raising a child with Down syndrome
- X. Resources that are available to participants

Participants were requested to choose as many options that were applicable for both figure 4.1 and figure 4.2 therefore representation of combinations are present where the frequency was five participants or more. For this reason, results are represented as a percentage value where applicable for the subsequent graphs yet are inaccurate when overlapping of responses is present and thus significant

number of participant responses rather than a percentage is reported for these cases.

In figure 4.1 it can be seen that participants generally felt anxiety (n=24,) once they discovered that the child had a diagnosis of Down syndrome followed by being upset (n=13). The remainder of the emotions experienced including the combinations was all relatively on the same level and did not show significance in comparison.

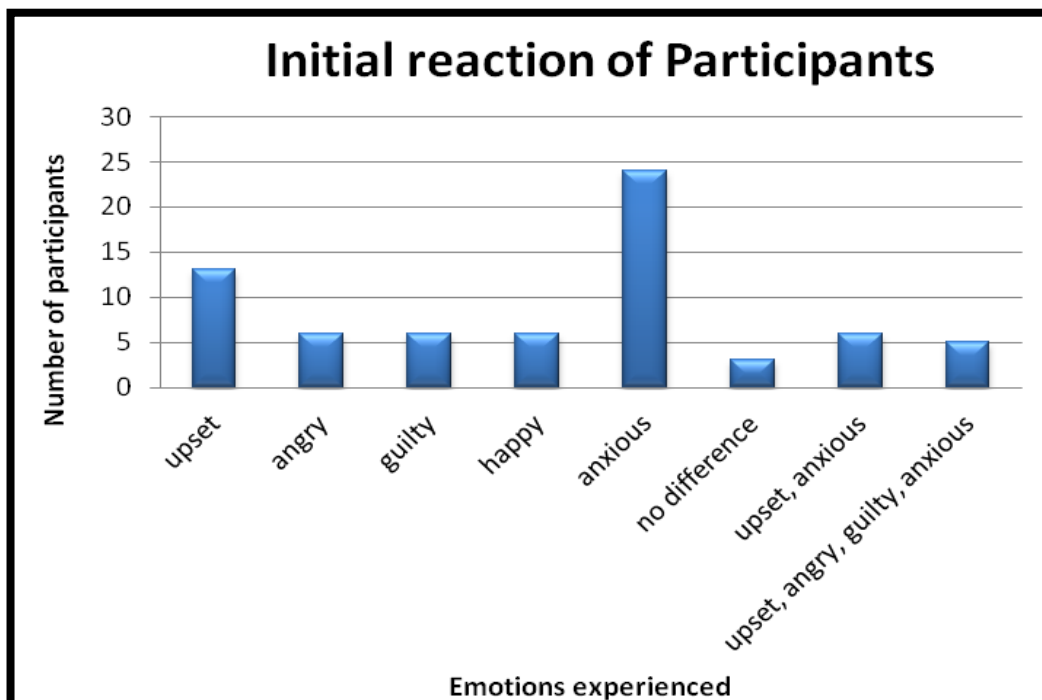


Figure 4.1 Initial reactions to discovering that the child has Down syndrome (n=69)

It can be noted that although initial reactions were not entirely positive, Figure 4.2 shows that a significant emotion experienced by the participants to the child initially was love (n=23). Feelings of confusion (n=17) and once again anxiety (n=12) was present and feelings of disappointment (n=9). It was noted that feelings of happiness (n=5) and indifference (n=1) scored far lower along with the combination of both love and anxiety (n=5).

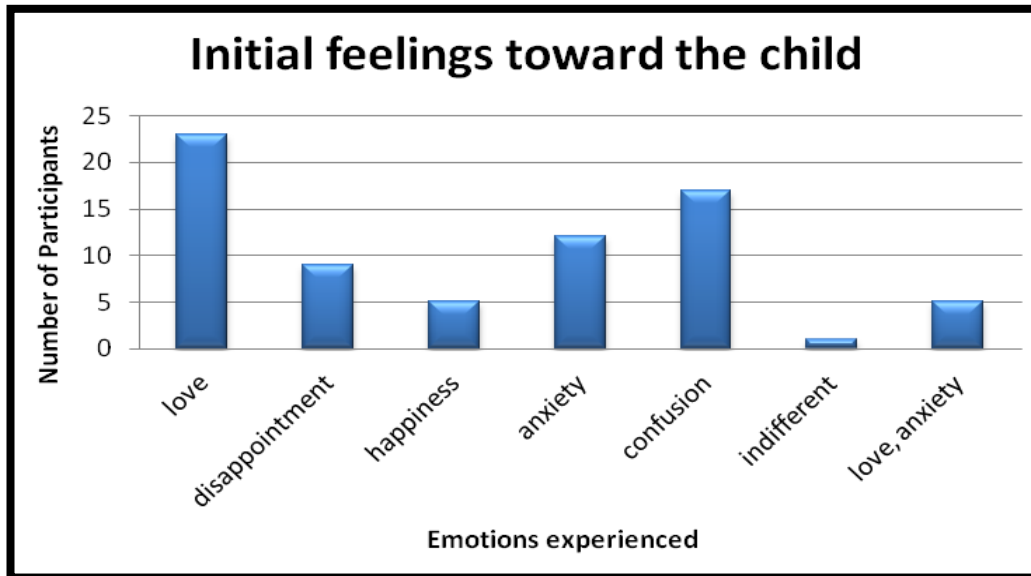


Figure 4.2 Initial feelings toward the child (n=72)

Participants were requested to indicate one choice for figures 4.3, 4.4 and 4.5 which may have influenced the results whereby participants chose the most applicable answer rather than a combination. It shows that majority of participants had limited knowledge (n=29) and understanding of Down syndrome initially. This was followed by participants who knew some information (n=14) and those who had never heard (n=8) of the syndrome. It was also evident that very few participants knew a lot (n=3) of information initially.

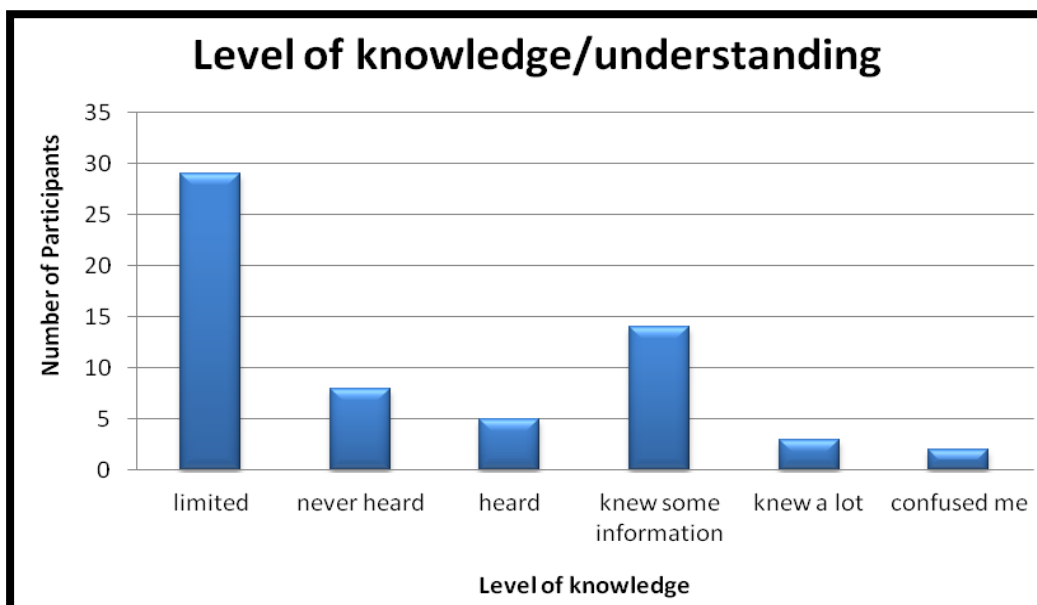


Figure 4.3 Initial level of knowledge/understanding of Down syndrome (n=61)

Figure 4.4 represents the participants' knowledge on the cause of Down syndrome. Graphically it can be seen that although participants' knowledge of Down syndrome was limited (See Figure 4.3, pg 58) majority knew that it is a medical condition (n=40) and not caused through a fault of their own (n=1) or that of the mother (n=1). A significant amount reported that currently, they did not know the cause (n=15).

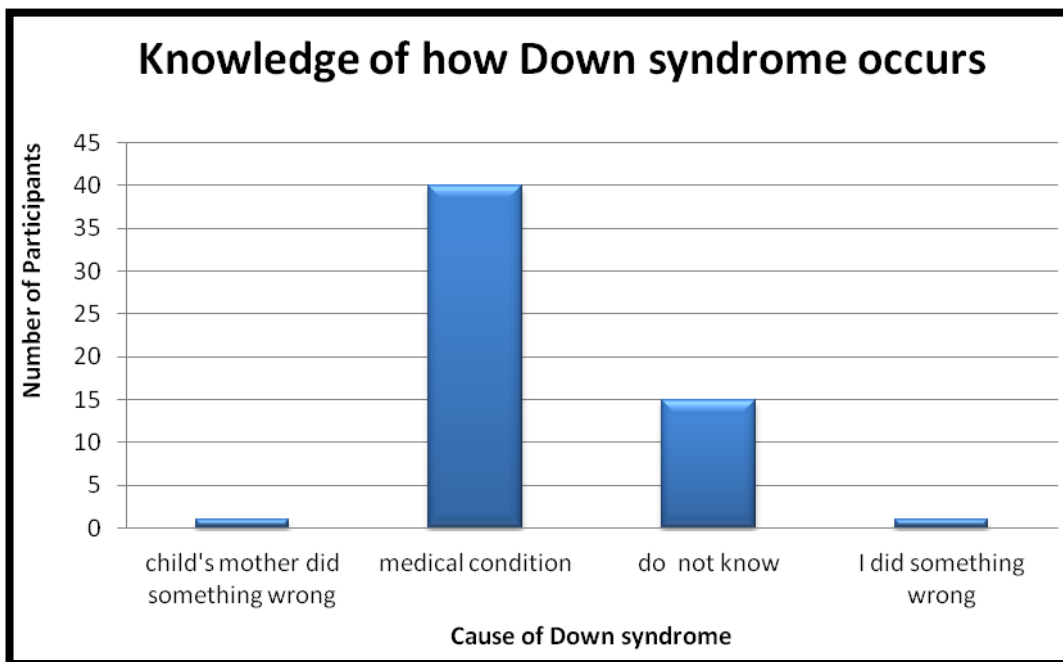


Figure 4.4 Participants' knowledge of how Down syndrome occurs (n=57)

In figure 4.5 it can be seen that there were some shifts in the participants' level of knowledge with regard to available therapy options. Initially participants showed divided knowledge as seen by high values for both no options (n=17) and most options (n=21). There is an increase in the choice of most options initially (n=21) to currently (n=26). Initially participants indicated that they knew all options (n=8) which substantially increased when participants indicated their current knowledge of all options (n= 24). This could represent participants' development when comparing initial to current awareness of therapy options.

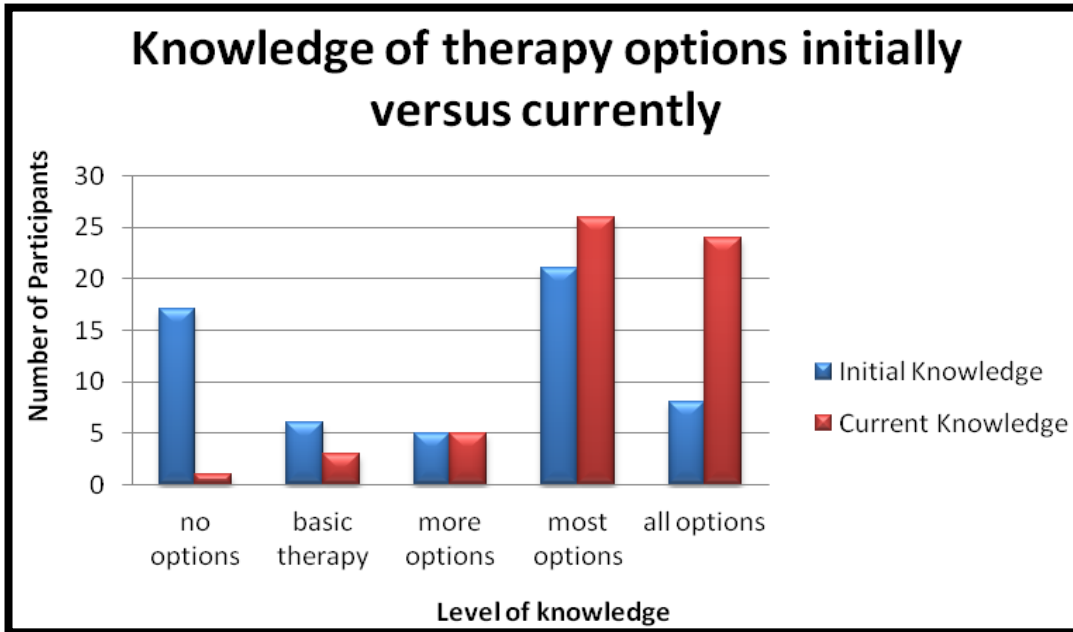


Figure 4.5 Participants' knowledge of intervention options available initially in relation to currently (n=57)

In figures 4.6, 4.7 and 4.8, participants were requested to choose as many options that were applicable. Figure 4.6 represents the participants' feeling when faced with telling their community and family about the child's diagnosis. It can be seen from the graph that high levels of mixed feelings were experienced for both the family (n=25) and in the community's (n=20) responses. A contrast is evident in terms of elevated levels of sadness (n=8) and anxiety (n=9) when facing family reactions in comparison decreased feelings of sadness (n=4) and anxiety (n=6) when facing community reactions. It is also notable that there is a marked difference in the level of indifference toward their community (n=20) knowing versus their family (n=12).

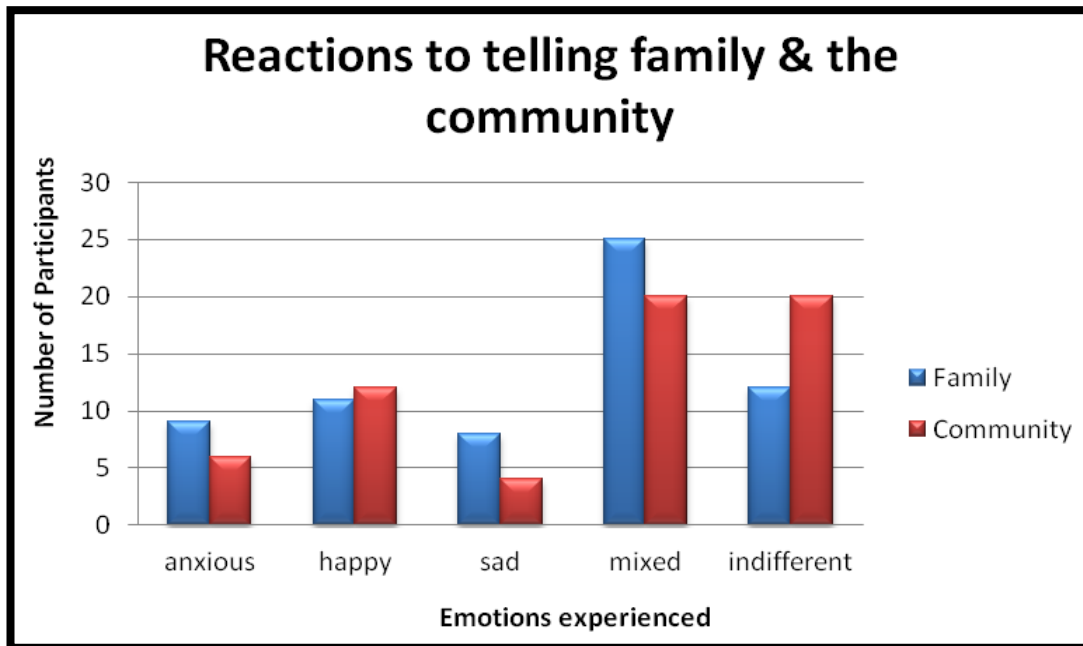


Figure 4.6 Emotions experienced when considering telling their family and community (n=62)

Figure 4.7 shows difficulties experienced with family as a result of caring for the child. As can be seen graphically, majority of participants (61.5%) did not experience any difficulties with family members followed by a small percentage who had challenges with their spouses (12.3%), other children (10.8%) and other family members (9.2%). As there was a low percentage of spousal difficulties, which is debatable in literature (McGrath et al., 2011, Povee, 2010, Goba, 2009) this further supported the need for further gathering of information in phase two.

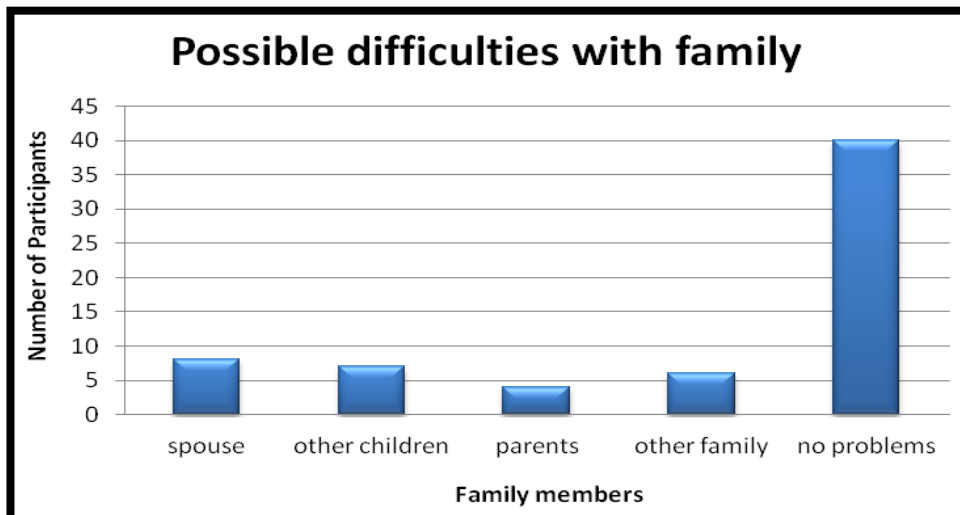


Figure 4.7 Possible difficulties experienced with family members as a result of the child (n=65)

Question four of the descriptive survey is significant and different to the above presented graphs as it requested responses with respect to the positive and negative aspects of raising a child with Down syndrome. The mean calculations were based on a weighted mean with a score of 0 for never, 25 for rarely, 45 for sometimes, 75 for often and 95 for always. The mean scores subdivided the responses into two groups:

Group one: had mean scores below 50 and refer to events that occur sometimes or less.

Group two: had mean scores above 75 and refer to events that often or always.

The group one questions referred to negative events related to coping with the child (which were found to be lower in frequency, below 50) and the group two questions to positive events (which were found to be higher in frequency, 75). Therefore positive events were recorded to be more recurrent in comparison to negative events.

Table 4.1 Relationship of positive and negative responses to the experience of raising a child with Down syndrome

Group 1 Questions		Group 2 Questions	
Negative responses	50 (less)	Positive responses	75 (more)
Sometimes		Often	
Less		Always	

Figure 4.8 is related to table 4.1 as it describes the emotions experienced when caring for a child with Down syndrome. Majority of participants experienced a sense of happiness (68.4%), followed by a mixture of emotions (14%) and the combination of happiness and a mixture (10.5%). Hopelessness (1.8%) and a level of fatigue (1.8%) showed decreased percentages.

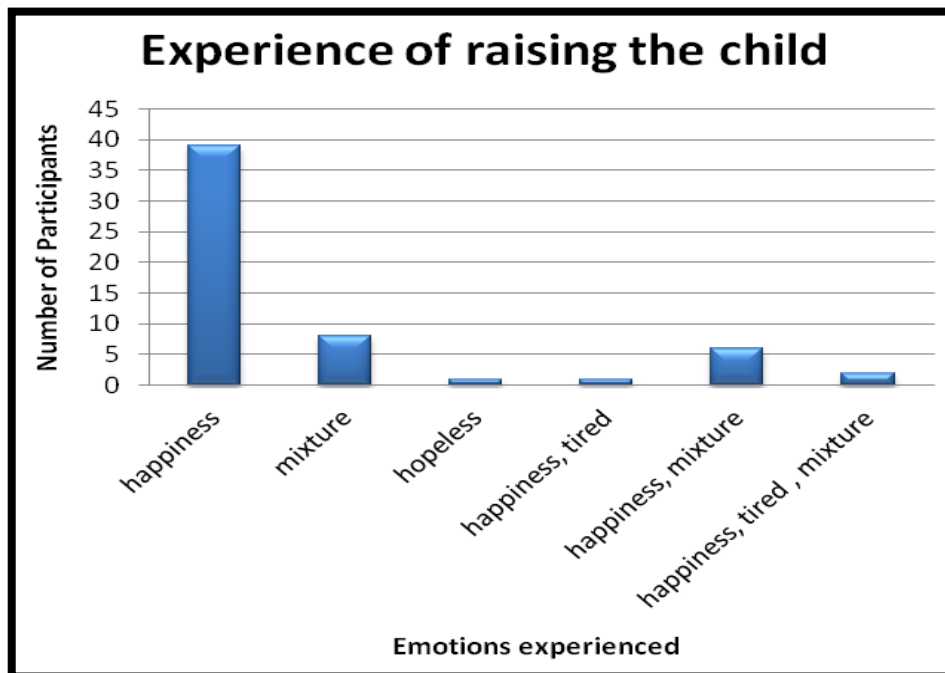


Figure 4.8 Emotions experienced as a result of caring for a child with Down syndrome (n=57)

Figure 4.9 represents the resources that participants had access to. In this question they were able to choose more than one option to show the array or lack of access to resources. Most participants had access to money (n=18), organizational support (n=16) and family support (n=14). Lower on the scale were all of the above (n=9), community (n=5) and caregiver support (n=6).

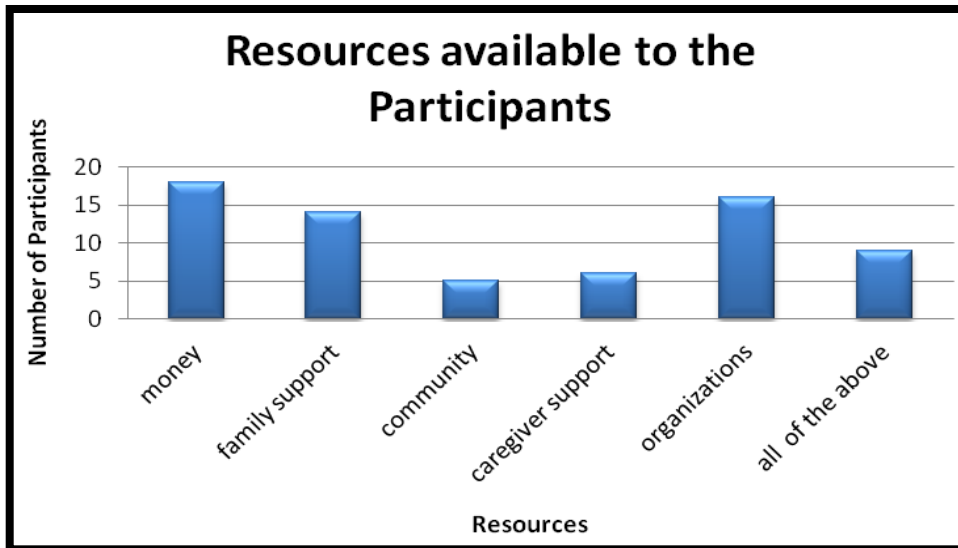


Figure 4.9 Represents participants' access to resources (n=83)

4.3.2 Summary of Quantitative findings

In the quantitative findings it can be seen that although an initial reaction encompassing negative emotions such as anxiety, the overall feelings toward the child are positive. This shows that the participants were able to gain acceptance and develop feelings of joy toward the child, however the manner in which this was achieved is not known. The lack of initial knowledge is stated and showed that participants gained knowledge over time when compared to initial discovery of the child's diagnosis yet the method of this is also unknown. Furthermore, the community and family reactions and perceptions require a greater depth of enquiry to understand the role that these individuals play. Thus it is vital to attempt to answer these questions through analysis of phase two to ensure that enriched data is presented.

4.4 Phase two: Demographics

Two focus groups and one individual, one dyad and one triad interview were conducted. Out of the 18 participants, 17 were female and one male. The ages of the caregivers ranged from 26 years to 56 years. Of the children cared for, five of the children were male and 10 were female with ages ranging between five and 11 years as per the inclusion criteria (See Chapter three, Inclusion criteria, pg 36)

4.4.1 Getting to know the participants

Please note that for the purpose of this research the participants and children have been given pseudonyms to maintain anonymity (See Chapter three, pg 51; Table 4.2, pg 65; Appendix 21) and confidentiality (See Chapter three, pg 51). However; the background information depicted is represented according to their subjective reporting. Full descriptions of participants can be seen in Appendix 21.

4.4.1.1 Focus Group one

Eight African women from lower socio-economical standing engaged in the focus group. Some of the participants knew each other from previous support groups and some participants had met for the first time. Initially the participants were reserved and cautious to share their view points but as the group progressed, greater sharing and ease with each other, the researcher and co-facilitator was noted.

Table 4.2 Focus group one

Name	Gender	Age	First language	Child age	Child gender	Child's diagnosis
Thembi	Female	43	isiZulu	Five	Male	Trisomy 21
Silindile	Female	36	isiZulu	Five	Female	Trisomy 21
Thando	Female	48	isiZulu	Six	Female	Trisomy 21
Fikile	Female	41	isiZulu	Eight	Male	Trisomy 21
Fanele	Female	42	isiZulu	Six	Female	Trisomy 21
Bongi	Female	43	isiZulu	Five	Male	Trisomy 21
Thandi	Female	28	isiZulu	Six	Female	Trisomy 21
Nonko	Female	48	isiZulu	Seven	Female	Trisomy 21

4.4.1.2 Focus group two

Four African females were interviewed from a low socio-economic background living within various communities within KwaZulu-Natal. The participants were not known to each other prior to the interview, however reported that they were happy to have met new mothers with so many aspects in common.

Table 4.3 Focus group two

Name	Gender	Age	First language	Child age	Child gender	Child's diagnosis
Busi	Female	56	isiZulu	Eleven	Female	Trisomy 21
Precious	Female	38	isiZulu	Seven	Female	Trisomy 21
Lungi	Female	35	isiZulu	Five	Male	Trisomy 21
Nozipho	Female	37	isiZulu	Six	Female	Trisomy 21

4.4.1.3 Individual Interview

Brenda is an empowered Coloured woman who has a loving and supportive family and friend network.

Table 4.4 Strong independent mom

Name	Gender	Age	First language	Child age	Child gender	Child's diagnosis
Brenda	Female	40	English	Six	Female	Trisomy 21

4.4.1.4 Dyad Interview

Craig and Sandra have a good support network as well as an older daughter who assists with caring for their daughter with Down syndrome.

Table 4.5 United couple

Name	Gender	Age	First language	Child age	Child gender	Child's diagnosis
Craig	Male	52	English	Eleven	Female	Trisomy 21
Sandra	Female	48	English			

4.4.1.5 Triad Interview

Jenny gains support from her other two daughters and domestic worker as well as occasional assistance from her sister.

Table 4.6 Mom, daughter and domestic worker; a formidable team

Name	Gender	Age	First language	Child age	Child gender	Child's diagnosis
Jenny	Female	42	English	Nine	Male	Trisomy 21
Kerry	Female	11	English			
Fran	Female	29	isiZulu			

4.5 Phase two: Findings

Themes that emerged from the qualitative data were the following (figure 4.10)

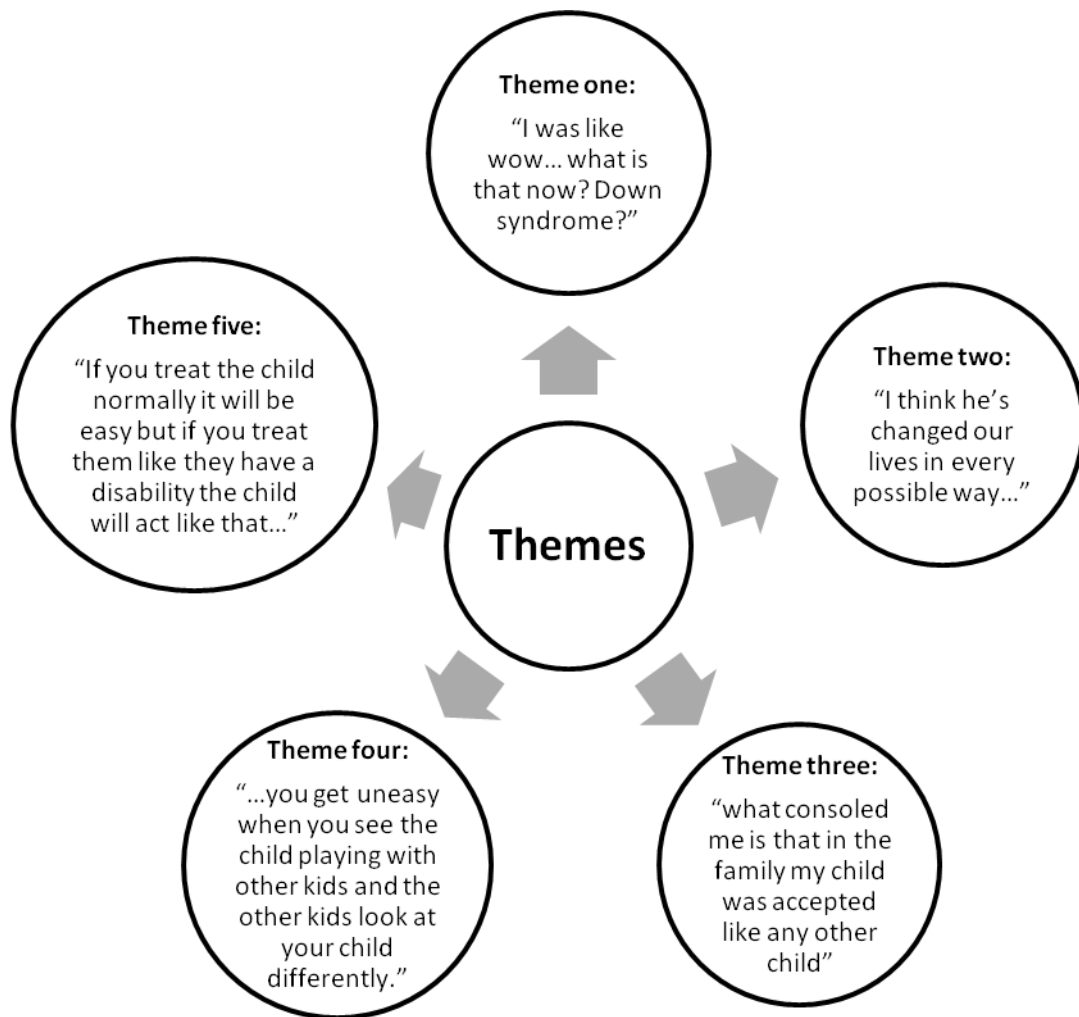


Figure 4.10 Themes

The qualitative data was analyzed utilizing thematic analysis (Joffe and Yardley, 2004). In vivo coding, emotion and descriptive coding were used to identify trends in the data (Saldaña, 2009, Kruckenberg, 2012), five main themes emerged.

4.5.1 Theme one: *“I was like wow... what is that now? Down syndrome?”*

[Thandi]



Figure 4.11 Theme one

From the data captured it became apparent that there was a general consensus of shock and sadness amongst the participants. Many of the responses confirmed that the initial reaction was coupled with a lack of knowledge as to what Down syndrome is and what the steps forward were. This lack of knowledge and surprised reaction was perhaps compounded by the fact that majority (94%) reported that they did not have the amniocentesis testing done whilst pregnant to determine whether Down syndrome was present prior to birth. Many participants stated that they were unaware that testing could be performed prior to birth. As a result participants were completely surprised by the diagnosis as they were expecting the birth of a typical child.

“I was shocked because I didn’t know what is Down syndrome and I was sad because at the family I was the first one who have a baby with a disability...”

[Silindile]

“Shock.... I’d say shock and then not knowing what Down syndrome was...”
[Jenny]

“I was shocked; I was very shocked because when I was told that my child was going to have a problem there was no one to explain to me properly as to what will happen to my child. I thought my child might not be able to walk, might not be able to talk or be able to do anything.” [Bongi]

“I was also shocked because I didn’t know what (sickness) my child had...”
[Fanele]

The lack of knowledge and understanding left participants feeling distressed and out of their depth as many did not know what the diagnosis would mean. This initial reaction was found to be exacerbated by a lack of understanding of how Down syndrome presents and how that would functionally affect their children. The participants showed that they were unaware of how the diagnosis would affect their lives and that of the child in terms of care and functional ability.

“I cry on that day... the time they telling me that my baby [has Down syndrome]... because I don’t understand what DOWN SYNDROME [said with emphasis] is.”
[Fikile]

“I was like wow... what is that now? Down syndrome? Maybe my child is going to be like all those children with saliva coming out ‘cause I was even thinking of leaving her in the hospital...” [Thandi]

Furthermore, many of the participants described a feeling of guilt and self-blame when discovering what Down syndrome was. Many of the participants expressed that they felt that they were to blame in one way or another. The participant’s age; whether they were above or below the risk age of 35 (Penrose, 1933), appeared to be noted frequently. In addition cultural influences played a role as participants expressed that due to religious, cultural or behavioural infractions they were being ‘punished’ by their ancestors and as a result they gave birth to a child with Down syndrome (Penn et al., 2010, Mhlanga, 2013, Naidoo et al., 2011).

“There is that feeling of guilt whereby you feel there is something that you did not do right along the way, sometimes you feel that when you sick and you drink pills [traditional and modern medicine] that maybe the pain pills you drank are what affected the child or something. But you are not at ease, because you always have that question in the back your mind as to what went wrong? [Bongi]

“Yes I did feel guilty because like I think there was something wrong I did to God, why God must give me a child like this? Because I was thinking everything I am doing I am doing ok, but I was like maybe there is this thing I did wrong that’s why I got a child like this or maybe my ancestors are punishing me for something that I did not know.” [Thandi]

“I was [guilty] because the doctors told me that if you are having a child above 35 years old and then you get more chances of getting a baby with Down syndrome. I was 40 at the time I was guilty...” [Thando]

“...I mean... there’s always some sort of guilt you know... my age, I had a big gap you know smoking, drinking, you know the normal things. You go through that whole sort of process you know...” [Sandra]

“I mean my side, I was drinking a lot in those days so I was also involved...” [Craig]

The general consensus, initially, was shock and confusion exacerbated by limited knowledge and fear of the unknown. However; this did not affect the participants’ initial feelings of love and acceptance for their child despite the challenges ahead. This was seen in the phase one findings and thus supports those results and supplements the specifics of information that was lacking in that phase. The participants reported that although they experienced a multitude of emotions at the time, majority, accepted their child from birth.

“I pretty much had accepted him anyway because I had already looked after him for 3 weeks and to me he was no difference to my other 2 kids... there was acceptance already...I would never change it for the world...” [Jenny]

“I couldn’t figure out what the fuss was, it’s my baby... I never rejected her; I accepted her as soon as you know I knew or whatever...nothing really changed or anything like that...” [Brenda]

“I had that question, asking God what did I do for Him to give me a baby like this but I saw there are many like me, even the younger mothers who are below that risk age. I then accepted.” [Fanele]

4.5.2 Theme two: *“I think he’s changed our lives in every possible way...” [Jenny]*

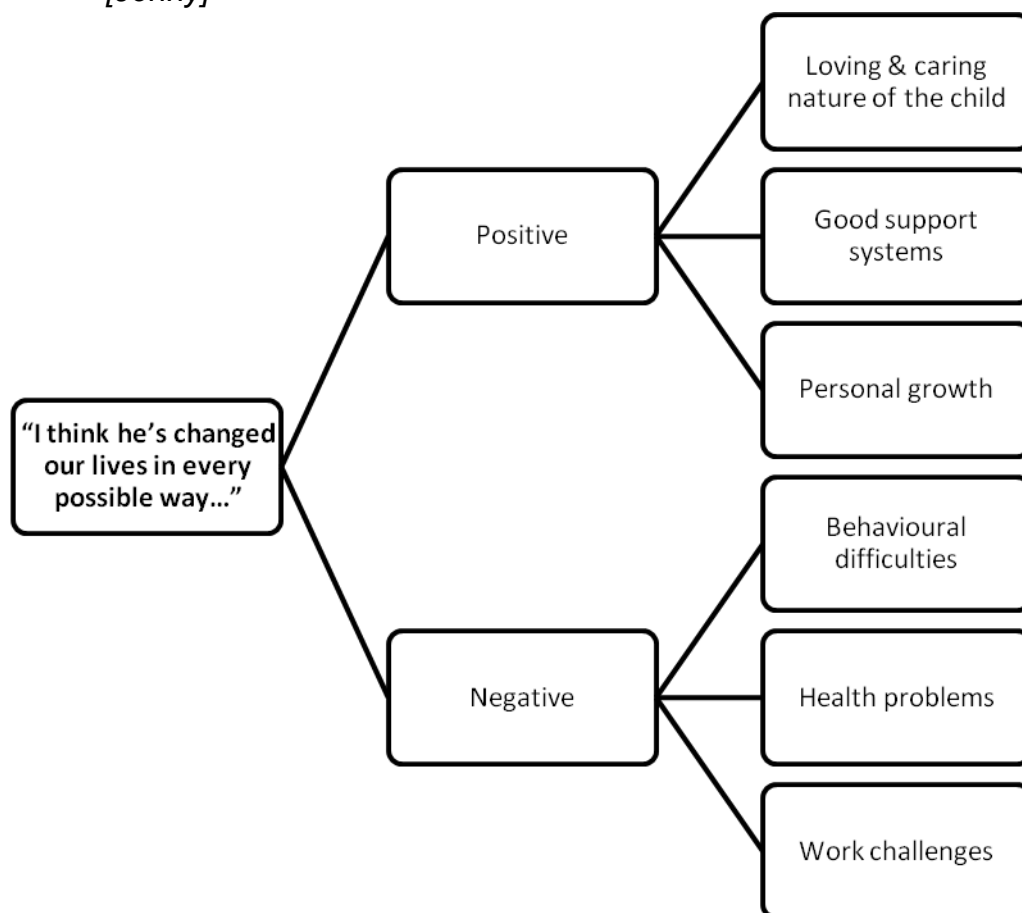


Figure 4.12 Theme two

When discussing what the experience of raising a child with Down syndrome was, many factors were raised. Both positives and negatives were discussed and both had contributing factors (See Figure 4.12, pg 71).

When the positive influences that the participants reported were identified, the loving and helpful nature of the child, support structures and caregivers' personal growth as a result of caring for the child were highlighted. These three factors were acknowledged separately, to allow for the impact to be realized.

A. Positives

Loving and caring: *"Yes I do have other children but none of my kids are as loving as she is." [Silindile]*

These children were found to be extremely warm and nurturing. The children were reported to readily offer hugs; introduce themselves to new people and have an ability to cheer up any family member. This was considered a large positive aspect for caregivers who found that although the child was naughty at times, it was difficult to be angry with them.

"Very loving very easy going, showing us the small things in life... [at the beach] he will run in the water and just be thrilled with the fact that the water is running over his feet. And you know it just makes you enjoy life and appreciate it more."
[Jenny]

"The nice thing about the child is that it is helpful, if you are packing she also wants to pack, if you are washing she also wants to wash, if you went to do your hair she will compliment you and say you look beautiful mom..." [Silindile]

"They have love because you find that sometimes you are feeling down they will come to you and want to sing.... even if you don't feel like singing you will find yourself singing....if they find a ball they will call you to play and you will play with them even if you were not feeling to play. If you are worried or stressed they always try to make the home a happy place...." [Silindile]

"What I like about them is that they are beautiful they are lovable... If someone comes to visit they run to go hug and welcome them, they are so loving..."
[Thembi]

“...she loves hugging and kissing too....she does so many things that us normal people can't do...” [Nonko]

“Everywhere like mine, everybody's calling 'HEY SNE MY FRIEND, HEY SNE MY FRIEND' sometimes I ask her who is this one? She doesn't know [laughing]” [Nozipho]

Support: *“when a child like this depends on you solely it's quite a bit of pressure so it's so important to have an extended support system” [Brenda]*

Support systems were noted to be a vital lifeline for participants as the responsibility of raising a child with Down syndrome is immense. Participants reported that interaction with other caregivers often provided them with a sense of solidarity and hope whilst support from others often allowed them to take a much needed break.

“...he [doctor] then sent me to a support group in Phoenix, that's where I found out that there are others it is not just me with a child who has this problem.” [Nonko]

“But once I got to a support group and saw other kids that grow normally although slowly, I found hope, what helped me was the support group so that I would be at ease.” [Bongji]

“ For now I would just like to say I am thankful to meet with other mothers...” [Thando]

Personal growth: *“it's been a very positive influence in my life.” [Sandra]*

Caregivers noted that they have positively developed as people as a result of caring for a child with Down syndrome. Beyond gaining knowledge on the syndrome, they stated that they have learnt qualities such as patience, acceptance and tolerance as a result of caring for the child.

“...it’s nice to stay with her because they teaching us a lot of things, like I never have a child with any disabilities at home but now I have known so many things.”
[Nonko]

“I know personally one thing that it’s taught me is... patience [laughs]” [Sandra]

“And I think that’s also changed for me you know I can look at another child, you know, a disabled child and I can empathize.” [Jenny]

“...there are good points, I promise you it’s taught me... I would never ever ever have changed the situation, not where I have got to now in my life... become an absolute... I don’t know... something worth living for.” [Craig]

The negative aspects that were highlighted within the interviews were behavioural difficulties of the child, health problems and caregivers finding it challenging to balance caring for the child and maintaining a vocational pursuit. Once again these factors were separated and the results depicted individually.

B. Negatives

Behaviour: *“it’s difficult raising a child with Down syndrome, she is really naughty...”* [Thando]

Negative factors included the stubborn and naughty behavior of the children. There appeared to be a consensus amongst the participants who all recorded variations of behavioural difficulties that add to the challenges of caring for a child with Down syndrome.

“It is difficult because when you are in a taxi the child is restless and pulls peoples hair and the people will look at you like you are crazy.” [Thando]

“...there is that naughtiness we were talking about and you see that when you have to go and leave her the person who is left to look after her will have second thoughts about staying with the child...” [Bongi]

“Other than stubborn... no... [laughs]... very stubborn... they want to do something now, they want to do it NOW and he can’t comprehend that there’s something to do before it...” [Jenny]

“I think maybe in the last year or so I have been battling with the behavioural side... Because I have realised now that you cannot negotiate with them, it’s almost impossible.” [Brenda]

“...you can’t go shopping with her because she refuses to get out of the car, you know, and that’s it boy, foot down. She locks the doors... Stubborn...you have never... I have never seen a kid as stubborn as that in my life. If it’s a no it’s a NO!” [Craig]

Health: *“...it’s difficult because these children are always sick; you are always in and out of different hospitals.” [Thembi]*

Health challenges have been recorded by all participants and were found to add stress to the lives of the caregivers. This was in terms of financial strain as well as concern for the child’s well being.

“When the child was small it was a problem because I always had a bag packed just in case the child suddenly got sick.” [Silindile]

“My child not only has Down syndrome but also has a heart problem, she’s had heart operations so what I tell myself now is if God keeps her with me its fine and if He wishes to take her it fine as well.” [Silindile]

“I’m talking about from one little cough in the morning to full blown bronchial pneumonia that night.” [Craig]

“Maybe I’m going to the hospital Monday, Tuesday, Wednesday then Thursday it [the child] doesn’t breathe nicely.” [Nozipho]

“...They [doctors] took the child to Albert Luthuli and she stays 9 months in the ICU...” [Busi]

“It [the child] just lie down for 8 months, it doesn’t move [when he got sick]! If you see it at the back here [gestures to her back] you see bones. If sometimes I’m going to the clinic and just putting for the baby injection I’m so worried if they taking the clothes [off]. Some of them say to me maybe that baby’s got AIDS [whispering]. I was crying!” [Precious]

Work: *“Like now I’m not working because of her.” [Fanele]*

Caregivers noted that working and caring for the child proves to be challenging especially without additional support from loved ones. This was exacerbated by health difficulties that require the caregiver be present to care for the child.

“As young as I am at age 28 I cannot work for myself because anything can happen with my child.” [Thandi]

“Yes when she was sick [had to leave the child with family members] and obviously you don’t have enough leave to stay away from work...” [Sandra]

“I’m working but because of the child I leave the work.” [Precious]

“...you see I got the work and then Sonto get sick and I have to leave the job to look after the child...” [Busi]

In addition to the positive and negative experiences of raising a child with Down syndrome, a trend emerged with regards to protective feelings of the caregivers towards the child. The caregivers felt that this was part of the experience of raising the child and was a necessary view point to adopt. The participants noted that often the children are or could potentially be mistreated and as a result they protect the children through creating a safe and controlled environment.

“And I can’t just leave her with anyone; I have to leave her with a person the one that I rely on her that she is going to look after her the way I look after her.” [Fikile]
“I think there’s always that fear you know of letting her out of your sight you know. It’s fine when she’s at school you know, she’s in that environment but anything outside of that is a big ‘WHOA’ you know...” [Sandra]

“Myself, I choose where Sonto must go... Sonto you can’t go to that person, to that house, especially that house because I don’t know what was going to happen when I’m not there.” [Busi]

“Because if the child she cries you will cry... definitely, if Sonto came crying, I cry.” [Busi]

“That’s why some people are saying we are making this child something big because you are always looking after them but you feel that the child is not happy...” [Nozipho]

4.5.3 Theme three: “what consoled me is that in the family my child was accepted like any other child” [Thando]

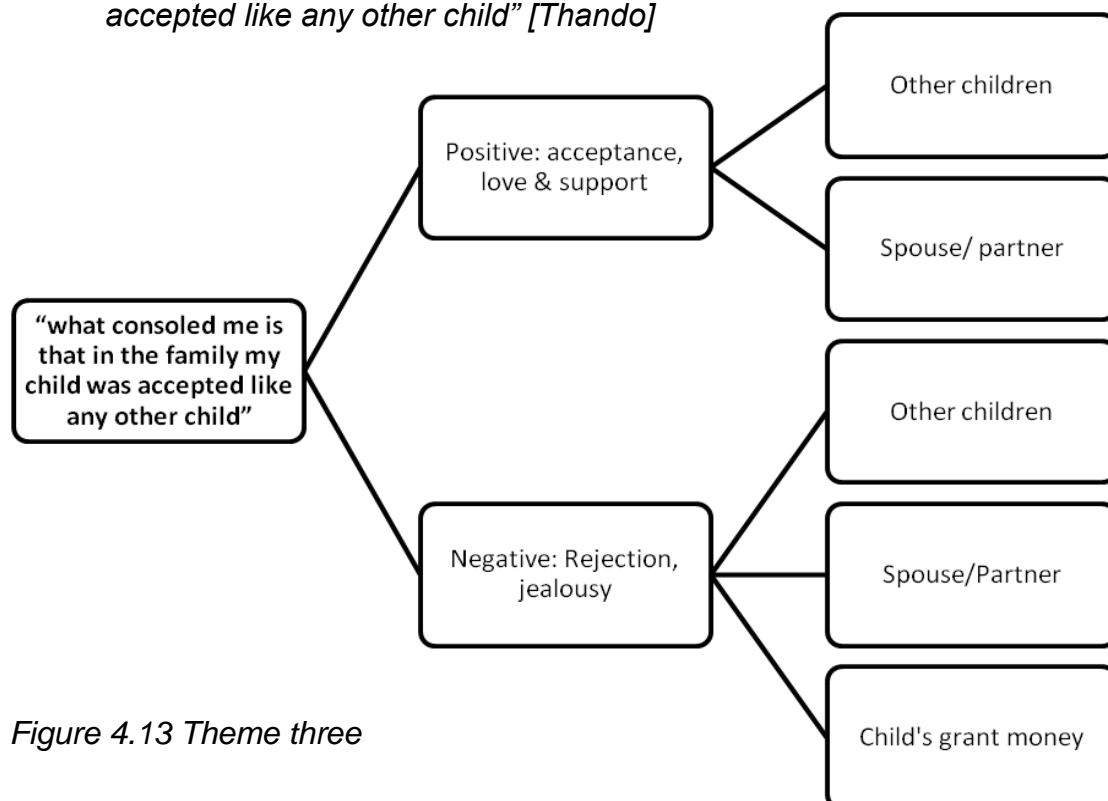


Figure 4.13 Theme three

Family involvement appeared to play a large role in caring for the child. It was reported to have had either a positive or negative effect based on the family's perceptions and attitudes toward the caregiver and the child. The participants recalled instances that either enhanced or worsened their experience.

"So you need to pray and hope for the family to accept the child because you can accept because it is your child but the family can be very un-accepting." [Bongi]

Positive experiences of acceptance, love and support with regards to other children and partners or spouses appeared to greatly assist the caregivers when describing their lives in a positive manner. Conversely negative experiences with other children and especially partners or spouses were also noted and accompanied by an undercurrent of resentment and sadness.

A. Positives

Positive factors include the positive attitudes of other children within the household as well as the caregivers' spouse/partner.

Other children: *"I think overall the experience within the family has been overwhelmingly positive." [Brenda]*

"For me I don't have a problem because my family doesn't have a problem they treat her like all the other kids even when she is at her paternal home there is no difference, but they do treat her special sometimes but not that much." [Nonko]

"At home there is no problem, they have seen that she is human she is like the other kids..." [Bongi]

"They love her, they love her so much....her brother who is 19 years the first thing he does when he comes through the door he calls Sne [daughter] and tells her to come to him and kiss him and hug him..." [Nozipho]

“They [her older two daughters] accept him [James] as he is, for whom he is, they actually help phenomenally. If anything it’s actually made the two of them more independent...” [Jenny]

“...my youngest would have been about 3 at the time and he could readily tell people. Actually his opening line would be [smiling] ‘my sister has Down syndrome’ So they quite open to it.” [Brenda]

Spouses or Partners: *“God blessed me with my daughter, my husband loves and accepts her.” [Nonko]*

“I told the father that she does get a government grant but I have never used it. He supports the child and gives me money for maintenance even though I am getting the grant...” [Thembi]

“Because my husband is understand what this baby got is Down syndrome, it’s got a problem [the child] it’s not a problem for the mama the mother, it’s not a problem for the father, it’s the chromosomes...I say thank you to God that my husband is next to me every time.” [Lungi]

“...the father also accepted it.” [Fanele]

Negative experiences with family life were noted significantly with spouses/partners whereas other children’s behavior toward the child appeared to be related to immaturity and jealousy rather than any form of maliciousness.

B. Negatives

As seen with the positive factors, negative attitudes of other children in the household and their spouse/partner can negatively influence the caregivers’ experiences.

Other children: *“...there will be other children in the household that feel that you give your child more love...” [Silindile]*

“My 13 year old said to me, he has never gone by car when going to school but this child goes with a car...” [Thando]

“They also love her but there is that jealousy when my other son asks why I always buy for her and I have to explain that it is because she is always in hospital and I tell him I will also buy for him when I get the chance.” [Fanele]

“...like if we plays games he normally gets upset if we tease him during the game or something like that, then he gets upset. If he starts to hit, he’s very strong.” [Kerry]

“Haley is very expressive so you know [laughing] if she wants attention sometimes she’ll blow her nose without having a tissue and that will just drive my son, the bigger one crazy.” [Brenda]

“...it actually took away a lot from my older daughter [raising Crystal]. She’s often made comments about how the difference is how I treat them and it’s very very true.” [Craig]

“She’s [other child] always said that it’s unfair... it’s unfair what Crystal gets away with. But we keep on telling her but you must understand that you know you can’t compare yourself. And they fight like cat and dog.” [Sandra]

Spouse or Partner: *“The father is negative... then the REST of the family is negative” [Nozipho]*

“...like mine, it was terrible because my husband he say he never have a child like this and he gone away till this today...” [Busi]

“Like mine... the father ignore the child then the peoples do the same...” [Nozipho]

“The fathers are running away because he says he doesn’t have a disability so he won’t give a child with a disability because at his home they don’t have a

disability... they talk as if we asked for the child who's got the disability so they running away." [Fanele]

"Yes it's had an effect in the sense that we've had a divorce but... I don't think he's [father] ever really accepted the fact that he's [James] a Down syndrome child..." [Jenny]

"I try to tell her father and the father tell me that he doesn't have any child like this, she [he] never got a child with a disability even in their family." [Precious]

In addition to spouse or partner and sibling reactions, finances played a role in the family experience of raising a child with Down syndrome. It became apparent that the child's grant money affected relationships and dynamics within the family. This was highlighted especially in terms of the rift it created between spouses or partners.

"Sometimes I have a problem because I have a mother in law, my mother in law always says.....when I need something from his [the child's] father they say this child will get a grant...take the grant of this child and do everything..." [Bongi]

"I say the fathers who run away are better because the ones who stay only stay because they know that there is some money that the child gets not realising that the money needs to be used for taking care of the child." [Thando]

"I also told him [the father] that the child will receive a government grant so now he asks me when is the child's money coming because I haven't told him that the child starting receiving the grant at the age of 1 year and the child is 5 years now... so he was supporting the child but I think he spoke to other people who have children with Down Syndrome and I think they told him that there is a government grant that the child should receive so now he only gives R200 a month." [Silindile]

"And the fact that the fathers want the government grant that we get the child, the father of my child is also not working, he was involved in a bus accident at work in

Cape Town so he is also receiving a grant but you find that he will concentrate mostly on the child's grant..." [Bongi]

4.5.4 Theme four: "...you get uneasy when you see the child playing with other kids and the other kids look at your child differently." [Fanele]

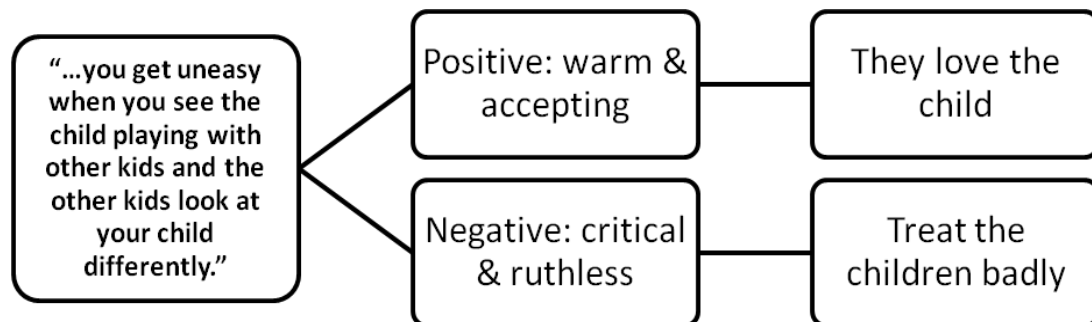


Figure 4.14 Theme four

It emerged that there are both positive and negative reactions involved when discussing how others respond to the caregiver and the child. The participants noted that there has been a mixture of responses from the community and general public.

"So some love them some don't" [Fikile]

From the opposing sides of the spectrum, the public may be extremely warm and accepting but they may also be critical and ruthless in their prejudice towards the child and their caregiver. The participants also noted that positive reactions enhanced their experiences whilst negative reactions hurt them deeply.

A. Positive reactions "I can say the community loves her" [Silindile]

"In my community there is no problem, everybody they like her." [Thandi]

"In my community they love her, she has her own jokes that she does and she has her own way of doing things, they have a name of calling her Chang Chang because of her eyes so it ended up sticking with her..." [Bongi]

“Most people are very accepting of him... He’s always with us, people accept him as he is” [Jenny]

“...for me it’s been absolutely positive. Maybe, I mean it’s been 6 years, I might have noticed people staring on 1 or 2 occasions but other than that I don’t focus on it you know?” [Brenda]

“Ooooh like my church... is a very good church. When I came with my child they ALL love her and she LOVES them. My church people are accepting my child nicely and my child is responding the same because they love her.” [Nonko]

“One day I went to the school Golden Hours... Yoooooh my child was a celebrity... I’m tell you... they hug you the teachers even the principal.” [Lungi]

B. Negative reactions *“we love our kids but they are mistreated in the community” [Thembi]*

“You find that the child will come back from the neighbour crying or the other kids will chase the child away...they are not accepted in the community...the community is not educated about children with Downs...” [Thembi]

“Some pretend that they like the child when they see you but when you are not there they don’t want the child...even when the child is just visiting they chase the child upon arrival.” [Bongi]

“In my community there is a school for children with Down syndrome and other kids make fun of children” [Silindile]

“One person in my family... not rejected... but passed a comment once and said I would have given it up for adoption or something like that you know...But I think, you know, people tend to look at a disabled child and say oh shame or it will never achieve or they have a negative attitude... I think automatically.” [Sandra]

“Even the community can’t accept, can’t accept. Even the neighbours and the small kids hit the babies. It’s hard, it’s hard, it’s hard.” [Lungi]

“...one day I went to the clinic, my child was sick, I think that day Sandile was one year 2 months. And the sister [Nurse] ask me how old is your child? And I whisper, I say she’s one year 2 months, and she said ‘HUH?’ and then she shout at me. ‘HUH’ what did you say? I said she’s one year 2 months. [Sister says]: Why she can’t sit on her own? You still looking [her] father in his eyes? You aiming to get another baby? In front of people... and I was crying... I was crying” [begins to cry] [Busi]

“That hurting so much [when the neighbour’s children steal her child’s toys and say]: “look at Dudu, she’s like a baby, how can Dudu not talk... she’s like me...” [Precious]

“You become very angry because they treat this child like something else, not a child.” [Nozipho]

Differentiation between positive and negative reactions was noted by the participants to be influenced in part by location. It was noted specifically by the rural participants that the difference between positive and negative community reactions in rural areas compared to urban areas was directly influenced by their home environment. Rural participants noted that in rural areas, the community and families live closely together and take an active role in the lives of each other (Swanson, 2007) which may be positive or negative. This is compared to urban areas whereby the urban participants live separately from neighbours and the community in general and thus only associate with whom they choose.

4.5.5 Theme five: *“If you treat the child normally it will be easy but if you treat them like they have a disability the child will act like that...” [Thandi]*

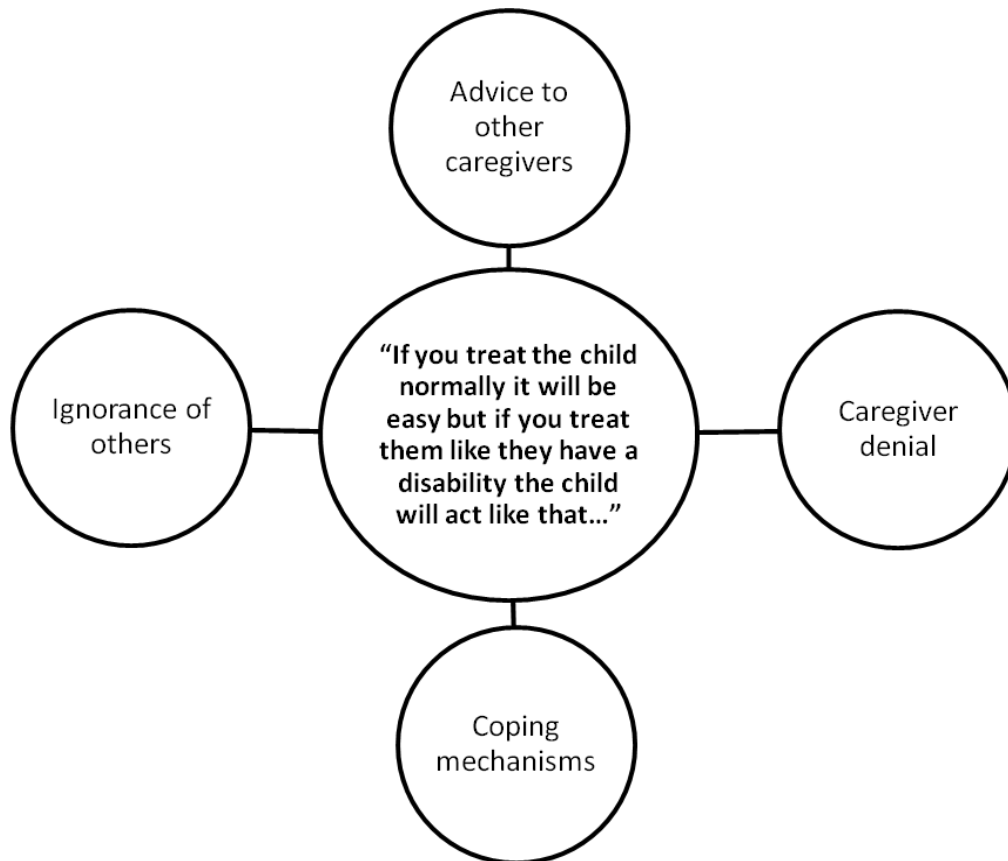


Figure 4.15 Theme five

From the data collected, it became evident that caregivers of children with Down syndrome had a wide range of wisdom to share with other caregivers. This advice related to new caregivers as well as those who had been caring for a child with Down syndrome for some time. The results showed what they have gained through caring for the child and therefore what they wished to impart to others. The advice focused on accepting the child with a positive outlook; taking each day at a time; exposing the children to the public; explaining to other caregivers what to expect; obtaining assistance when needed and the need to educate the public with regards to Down syndrome. The participants noted that caregivers are often reluctant when acknowledging deficits in the child and would rather live in denial. The participants expressed the importance for caregivers to identify impairments and act accordingly (such as special school placement or additional assistance).

“As parents with children who have Down syndrome, we need to be proud of that, so that another parent will be able to come out in the open if her child has a similar condition...” [Silindile]

“Maybe sometimes you can tell her [another caregiver with a Down syndrome child] about the beauty of your child...you can say your child has Down syndrome but is able to do so many things.” [Silindile]

“It’s just that we need to come together with other mothers so that if you do see a mother with a child who has Down syndrome you can be able to explain to her what Down syndrome is, it’s not a disability that means that your child will not be able to do anything...” [Bongi]

“You just got to love them and accept them for who they are. But I think they do that to you from the start. That’s how we’ve just accepted him and carried on... loved him...you know what they still your children no matter what they look like or how they behave or anything when you take them out.” [Jenny]

“I think one of the first things I came across in one of the books my best friend gave me about raising a child with Down syndrome is that as early as possible, take them out into the public, you know if people stare, so what? So, that early exposure I think is once piece of advice that I can give parents with special needs. Don’t hide your child. If they going to throw a tantrum, they going to throw a tantrum everyone else must learn to deal with it.” [Brenda]

“...don’t try and look at the end picture... just look at the problem you are dealing with now because the hurdles are too big. If I look back and I try to reach to where we got now I would have given up.” [Craig]

“Encourage her... whatever she does... encourage her... they can learn.” [Busi]

The participants agreed that often as parents and caregivers, they showed a level of denial when it came to difficulties that the child was experiencing either at

school or in general. The participants felt that it was essential to take action to assist the child and improve their chances for a more productive future.

“Sometimes we as parents don’t pay attention so I tell them if they hear from the school that the child has a problem they should go and enquire and find out what problem the child has...” [Fanele]

“I often tell parents that you need to look at your child and how they are...” [Fikile]

The participants identified methods to assist with coping. These were highlighted specifically in the form of support systems that would allow for the caregiver to take time for them and not reach burn-out. They noted that assistance with caring for the child, in any form such as a family member, community member, hired help and the like greatly improved their quality of life when dealing with a challenging time period.

“The main thing that you need is support and understanding because you virtually know nothing about learning. It takes a long time to know about things and you don’t know, you’re learning as you go along. So with having people you can fall back on, ask, help... that is huge.” [Jenny]

“When a child like this depends on you solely it’s quite a bit of pressure so it’s so important to have an extended support system” [Sandra]

“You’ve got to have your time-out where I just put things down, I’ve had enough and I just walk, Sandra, do what you want...” [Craig]

Caregivers identified that the decreased knowledge surrounding Down syndrome needs to improve to promote awareness and understanding in order to diminish ignorance. The participants expressed the need to educate other caregivers and the public to assist in raising the child as well as to improve the child’s quality of life in terms of public attitudes. A few participants noted that it would be beneficial for expecting mothers to have the screening and tests done, not for the purpose of termination necessarily but to allow for the woman to begin to prepare herself.

“More information needs to be put out there and more people made aware of it... there’s not enough awareness.” [Jenny]

“Get your kids involved, other siblings involved immediately, get your family involved, get them to understand what it means to be Down syndrome because I think it’s so much more about ignorance, that people are afraid of Down syndrome children.” [Brenda]

“I would think it might be better for women to do more screening beforehand. But that doesn’t mean that they must reject the child it must just be that they’re more prepared when it does happen.” [Sandra]

“And the only thing that I notice and I tell the young mothers, these days 21 years, 23 years they get these children...” [Nozipho]

4.6 Summary

“Young mothers... they must be strong, they must accept this child because if they doesn’t do that they are not going to cope with this thing, because it is heavy it’s not easy” [Nozipho]

Many factors were discussed and to a large extend positive and negative factors influenced caring for the child in terms of community, spouse/partner and other children. The challenges and the benefits of raising the child were particularly highlighted. These included positive aspects such as the loving nature of the child but also included negative elements such as the health condition of the children and the financial implications.

The acquisition of knowledge and the experience of raising the child were influenced by many aspects such as family and community influences that spanned over more than one theme.

In the quantitative and qualitative data, participant reactions, feelings toward the child, the degree of knowledge at the time versus currently and the influence of family and the community were represented. Graphs and tables for both data

approaches were utilised to allow for a greater understanding of what emerged as a result of the descriptive survey and the focus groups and interviews.

“You must love your child so much that the other people next to you will love your child... .. and you must ACCEPT the child so that the others can do the same. And you must be strong, because if you are strong if there’s anybody talking something, telling silly stories you will not listen to them...” [Nozipho]

This aids in understanding the severity of caring for a child with Down syndrome. Although positive aspects have been highlighted, there is a significant point from the participants that urges carers to accept the child and to show a sense of resilience. All children are different, so too are children with Down syndrome. They look differently and they behave differently yet the message of acceptance pervades.

CHAPTER FIVE

DISCUSSION

5.1 Introduction

Within this chapter, the results, as represented in chapter four are collaborated and integrated to produce meaningful comments on the constructs of caring for a child with Down syndrome. The participants' initial reaction, level of knowledge, family and community influences are discussed along with contributing factors and advice given to other caregivers. The qualitative and quantitative results are compared and contrasted with the aid and support of the literature reviewed (See *Chapter two, pg 9*).

5.2 Discussion

A total of 57 participants engaged in phase one, the descriptive survey, and 18 participants engaged in the focus groups, individual, dyad and triad interviews. The collaborative findings of the survey, interviews and focus groups are explored in the subsequent sections.

5.2.1 Initial Response, What is Down syndrome? (See *objective 1, pg 4*)

As reflected in both the qualitative and quantitative results, the participants' initial reactions when discovering that the child had Down syndrome encompassed shock, sadness and anxiety (See *Figure 4.1, pg 57; Theme 1, pg 68*). It must be noted that although sadness and shock were not specified in the quantitative survey as options for initial reactions, the intensity of the emotion is comparable. The qualitative and quantitative findings both show that the initial reactions were fueled by strong and powerful emotions. This relates to the literature whereby caregivers have been found to display emotional reactions to discovering the child's diagnosis (Lam and Mackenzie, 2002, *Down Syndrome: Parents Sharing.*, 2014). This is even evident within an international context whereby the birth of a child that is not considered 'normal' evokes feelings of grief as the possibilities of typical development are eradicated (Kearney and Hyle, 2003, Lam and Mackenzie, 2002, *Down Syndrome: Parents Sharing.*, 2014). Furthermore, studies show that there is then a sudden need for the caregiver to adapt to the novel

situation (King et al., 2000) which increases the intensity of the feelings experienced. The caregiver has to then internalize the child's diagnosis as well as the emotional and physical demands that accompany caring for such a child; which relate to the initial emotions experienced.

As majority of the participants noted that they did not perform the amniocentesis testing or any specialized screening to determine whether Down syndrome was present prior to birth; they reported that they expected a healthy, typical child. As part of the South African National Policy, free testing is provided to expecting mothers, however this is only the case for advanced maternal age (Urban et al., 2011). Many of the participants expressed that they were unaware of testing that could be performed and thus did not enquire about this service. In addition, some participants reported that they were not over the age of 35 and thus did not anticipate any difficulties with the child. This lack of foreknowledge was reported to have contributed to the feelings of shock, sadness and anxiety as the caregivers were unaware that the child would have Down syndrome. The subsequent birth of a child with Down syndrome and the loss of the ideal of a 'perfect' child has been documented and can be seen in the study to result in emotions that are not always positive (Lampret and Christianson, 2007, Lam and Mackenzie, 2002, Down Syndrome: Parents Sharing., 2014, Holdt, 2008). These emotions have been acknowledged and relate to grief and despair (Kearney and Hyle, 2003) as well as the emotions depicted by the participants within this study (Lampret and Christianson, 2007, Lam and Mackenzie, 2002). Thus the participants were ready to give birth or to care for a 'normal' child and instead were faced with a major life event (King et al., 2000).

The emotions of shock and anxiety were most significant as responses for the participants in phase one (*See Figure 4.1, pg 57; Theme 1, pg 68*). It became apparent that majority of participants in both phases reported to have had limited knowledge about Down syndrome which was a contributing factor in their initial reactions (Engelbrecht et al., 2001). Furthermore, participants in both phases expressed a lack of understanding in terms of the presentation of Down syndrome. The participants in phase two reported that they were unsure what the syndrome would mean for the child on a functional basis in terms of growth, development

and ability. They further noted that they were uncertain how the child's presentation would affect them personally in terms of emotional and physical demands. According to the literature, caring for a child with 'special needs' increases the demands placed upon the caregiver in the sense that they are responsible for ensuring all the child's needs are fulfilled (Gcaza and Lorenzo, 2008, Jakobsson et al., 2007). This added to the anxious feelings within phase two as some described fears of severely impaired children with no hope of any functional independence. The participants were unaware of what caring for the child would be like as they had no point of reference in which to compare the experience. This only served to add to the initial feelings of panic and surprise. The lack of understanding was further exacerbated as seen in both phases by impaired knowledge with regard to therapy options which only perpetuated the participants' decreased expectations for the child's abilities.

5.2.2 Understanding. How does Down syndrome happen? *(See objective 1, pg 4)*

When considering the etiology of Down syndrome, the following were noted: Within the quantitative results *(See Chapter four, pg 55)*, participants showed that they understood that it was a medical condition relating to chromosomal abnormalities (Silverman, 2007) rather than attributing the syndrome to a fault of their own. This contrasted to the qualitative data *(See Chapter four, pg 55)* which in many participants indicated feelings of self-blame and guilt. It is possible that participants chose the 'most' correct answer within the descriptive survey being Down syndrome is a medical condition rather than I did something wrong as well as possible influence by other participants completing the survey together.

Notwithstanding this, the expression of feelings of guilt was a prominent factor within the interviews and focus groups in phase two. Many of the participants expressed feelings of blame due to their advanced age at the time of conception and birth. According to the literature, advanced maternal age, 35 years and above are considered to increase the risk of the occurrence of Down syndrome (Penrose, 1933, Sherman et al., 2007) and participants felt that they were the cause for the birth of such a child. Participants also expressed perceptions that omission of one or more religious or cultural acts resulted in the abnormality of the child, which is

often the case within South African communities and evident in literature (Lansdown, 2002, Naidoo et al., 2011, Botha et al., 2006, Mhlanga, 2013, Penn et al., 2010). Many participants felt that in one way or another they were being punished by God or their ancestors for infractions that they had committed. This is commonly related to cultural upbringing and bias as many individuals are ignorant to the fact that the syndrome is most likely as a result of gene over-expression (Silverman, 2007) as found by recent research into the etiology (McGrath et al., 2011).

Perceptions of self-blame, limited knowledge and the initial reactions of shock coupled with sadness may contribute to the emotions of participants when faced with telling their communities and families about the child's diagnosis (*See Figure 4.6, pg 61*) (Lam and Mackenzie, 2002, Jakobsson et al., 2007, Engelbrecht et al., 2001). It is possible that initial feelings of anxiety as seen in phase one and shock in phase two may in part be related to revealing this news to their family members as seen in figure 4.6. Participants in phase one showed a higher regard for what their family thought and felt in comparison to that of their community. Participants in phase one reflected higher levels of anxiety, sadness and mixed emotions as well as decreased levels of happiness when faced with informing their family. According to literature the birth of a child with a disability adds stress to the family unit due to the demands that caring for the child brings (Kaufman and Uhlenberg, 1998, Baxter et al., 2000).

Although their family's perceptions appeared to be of greater value, the participants in phase one did represent high levels of mixed feelings toward telling their community members. This could be attributed to the high levels of stigmatization and prejudice, as found in the literature, toward children who are not considered 'normal' by communities within South Africa (Lansdown, 2002, Botha et al., 2006, Mhlanga, 2013, Penn et al., 2010). This is further linked to the cultural opinions of the community attributing negative life events to bad spirits or inadequate cultural practices (Lansdown, 2002, Mhlanga, 2013).

Initial reactions of the participants were affected by the sudden diagnosis, decreased knowledge, as well as anticipated family and community reactions. The

participants placed emphasis on not knowing what the syndrome was which affected their perceptions and attitudes toward what caring for the child would be like in the future.

5.2.3 Feelings toward the child *(See objective 1, pg 4)*

According to the participants, as seen in both qualitative and quantitative findings, a negative perspective has been associated with the initial period encompassing the birth of the child with Down syndrome and their subsequent reaction (Down Syndrome: Parents Sharing., 2014, Naidoo et al., 2011). This extended to following stages of realizing the necessity for knowledge acquisition as well as sharing the child's diagnosis with the family and community. Despite the influence of these factors, the participants' initial emotions toward the child rather than the situation have proven to be positive and unchanged by the compounding challenges. The participants showed feelings of love toward the child as seen in the survey and reported during the focus groups notwithstanding the diagnosis *(See Figure 4.2, pg 58; Theme one, pg 68)*. Higher levels of confusion and anxiety were expected due to the multiple exacerbating factors, however, the elevated feelings of love toward the child was emphasized by majority of the participants. This relates to studies that show that the occurrence of a disability in the family results in the caregiver/s having to adapt their perceptions and adapt a sense of acceptance in order to problem solve and cope (King et al., 2000, Hodapp, 2007, Jakobsson et al., 2007, Mhlanga, 2013).

The majority of the qualitative participants noted that they felt a sense of acceptance toward the child once the initial astonishment had subsided which is concurrent with literature (Jakobsson et al., 2007, Hodapp, 2007, Down Syndrome: Parents Sharing., 2014, Naidoo et al., 2011). This may be deduced from the quantitative findings as the initial reaction was somewhat negative but still resulted in positivity toward the child, which may suggest a level of acceptance.

The participants in phase two expressed that although the child was different; they still felt possessiveness and a sense of protectiveness, irrespective of the difficulties that lay ahead. The participants therefore began to adapt to the novel situation, towards acceptance that the circumstances are permanent and that in

time it will become part of the norm (King et al., 2000, Lam and Mackenzie, 2002, Holland, 1996).

The participants expressed that caring for the child had in fact become part of daily life which is aligned with research (King et al., 2000). Once acceptance had been adopted, taking care of the child was considered as 'normal' as caring for any other child. In this way, as seen in research, the participants showed an adaptation to a stressful situation and found means to cope with the factors involved as individuals would with any stressor (Hodapp, 2007, Jakobsson et al., 2007). The positive and negative aspects of caring for the children were however noted in great detail (See Figure 4.12, pg 71; Theme 2, pg 71).

5.2.4 The positive factors of raising the child with Down syndrome (See objectives I-IV, pg 4)

As positive factors were eluded to in the quantitative results (See figure 4.1 pg 57), further details were needed to ascertain what those factors are. Thus the qualitative results are discussed.

Positives were described in phase two in terms of the child's loving nature whereby the caregiver had met many people through the child's uninhibited interaction with others. Many of the participants expressed during the focus groups and interviews that the children had the ability to elevate their mood during times of hardship. Positive aspects noted by the participants and supported by the literature included personal growth and acquisition of good support systems (Boyd, 2002, Lam and Mackenzie, 2002). The support groups described by participants included: family members; community members and structured groups such as The Down syndrome Association KwaZulu-Natal (Boyd, 2002, Lam and Mackenzie, 2002).

The participants in phase two noted that they had gained and developed as individuals as a result of caring for the child which is supported by research (Lam and Mackenzie, 2002). Many reported that they acquired a greater ability for patience and tolerance whilst others stated the impact the child had made in their

lives. Many expressed that they would not change the situation of raising a child with Down syndrome if they had the opportunity.

Family and community acceptance were also considered large factors in the experience of raising the child. It is notable that most of the urban participants (67%) noted positive reactions of family and community members whereas there was a divide amongst the rural participants. The urban participants (33.3% of the total participants) noted very few negative reactions and reported that they only associated themselves with positive individuals. Of the rural participants (66.6% of the total participants), 41.6% expressed positive reactions whereas 58.3% negative community and family reactions. The rural participants noted a factor that affected these numbers and allows for the differentiation between the urban and rural population; the difference being their home environment. Rural participants described how the community and families live closely together and take an active role in the lives of each other (Swanson, 2007) which may be positive or negative, whereas the urban participants associate with whom they choose.

Participants generally described a more stable and content lifestyle when their spouses or partners, other children and community members showed warmth and positive attitudes towards them and the child. The unifying of family members improved the caregivers' quality of life and showed that during times of hardship, they were able to unite as a family, as seen in the literature (Jakobsson et al., 2007, Goba, 2009). Many participants described how their other children and partners engaged with the child and took an active role in their lives which often reduced the stress and burden of having to care for the child solely (Gcaza and Lorenzo, 2008, Diener et al., 1985, Beresford et al., 2007, Boyd, 2002).

In addition, as community members live close together in rural areas this may contribute to positive or negative factors. These could be related to love and support when aiding with child care or in terms of negative attitudes and stigmatization. On the positive side of the spectrum, many community members were noted to assist with caring for the child when the caregivers were otherwise engaged as well as adopted warm and welcoming attitudes toward the child (Sonn and Fisher, 1998). This can be related to the South African concept of Ubuntu or

togetherness whereby there is a sense of solidarity amongst the community members (Swanson, 2007). According to Ubuntu principles, South Africans often unify in times of adversity in order to overcome hardships as a unit (Swanson, 2007). In the cases of positive reporting, the community in this sense formed support systems that enabled the caregivers to share the demands of caring for the child when necessary (Boyd, 2002, Sonn and Fisher, 1998, Swanson, 2007).

Support systems played a vital role when participants described their experiences during the focus groups and interviews. The majority of participants noted that they would not have been able to adopt an accepting outlook and manage with the pressure of caring for the child without their support networks (Boyd, 2002). According to research and reported by the participants, this assisted in reducing fatigue and the chance of burn-out whereby allowing the caregiver time for themselves (Boyd, 2002, Conrad and Kellar-Guenther, 2006, Ainbinder et al., 1998b, Mhlanga, 2013). These support systems were noted as not only family and community members but also the support groups run by The Down syndrome Association KwaZulu-Natal and the various groups at the hospitals within KwaZulu-Natal (*See Chapter one; Figure 3.8, pg 37; Figure 3.9, pg 37*).

Positive factors reported by the participants were weighted on the attitudes and reactions of others. Positive reactions by family, community and support groups assisted in the caregivers' constructive perceptions. This in turn assisted in their noted personal growth which participants felt was a beneficial result of caring for the child.

5.2.5 The negative factors of raising the child with Down syndrome (*See objectives I-III, pg 4*)

Conversely, the negative factors described by the participants in phase two were reported to be vast and greatly impacted their lives (*See Chapter four, pg 74; 79; 83*). The participants noted the toll that the negative aspects of the child and attitudes of others have taken on them. This is aligned with the literature that supports that this adds to the difficulties of caring for a child with deficits (Lam and Mackenzie, 2002, Rajh, 2005). Furthermore research supports the increased physical and emotional demands placed upon a caregiver when raising a child

with special needs due to the child's constant need for care (Lam and Mackenzie, 2002). This was qualified by the participants reported experiences.

When exploring the negative factors associated with the child themselves, all the participants noted health challenges. This is noted in multiple literature sources to occur amongst children with Down syndrome (Silverman, 2007, Sherman et al., 2007, Bross et al., 2008, Bruyère et al., 2005, Lam and Mackenzie, 2002, Ward, 2002, Thomas et al., 2011, Marchal et al., 2013). These health difficulties, according to available research as well as reported by the participants, range from respiratory difficulties to heart defects (Silverman, 2007). The participants specifically noted sinus problems, cardiac dysfunction and scoliosis to be prominent deficits. The presence of health impairments was noted to increased the demands and strain placed upon the participants (Gcaza and Lorenzo, 2008). Participants recalled difficulties when caring for the sickly child. This included staying up all night in order to care for the ill child; sleeping on hospital benches in order to stay with the newly admitted child as well as being constantly aware of the time in order to administer the child's medication on time. Participants recalled occurrences whereby a common and non-threatening illness such as influenza developed into a serious infection such as Bronchial-pneumonia within a short period. Many recalled how they feared on more than one occasion that the child would not survive.

The challenges were only exacerbated by the numerous hospital visits that caregivers reported. Majority stated that they attended various hospitals often, sometimes three times a week. Participants also recalled months when the child was hospitalized and in the intensive care unit. This resulted in immense pressure placed upon the caregiver whilst attempting to provide adequate healthcare and fulfilling their needs (Lam and Mackenzie, 2002). Furthermore, this was compounded by the costs involved in transport, medication and caring for the child (Bross et al., 2008). This is supported by research which states that the health difficulties, costs incurred and emotional strain experienced is often demanding for the caregiver especially those who constitute part of the lower socio-economical standing (Lam and Mackenzie, 2002).

Financial strains were only further compounded by the participants' decreased ability to maintain vocational pursuits. This was also found in international research which showed that the demands of caring for a child with impairments reduce the caregivers' time to engage in other meaningful activities (Lam and Mackenzie, 2002). The participants noted that caring for the child required constant attention and with persistent health problems, employers were not prepared to offer enough time off, paid nor unpaid (Lam and Mackenzie, 2002). This was mainly depicted with caregivers from rural communities without concrete qualifications. They noted that they would not be at a job for a lengthy period of time before their child required additional care. Employers were reported to not be understanding and as a result would rather replace the caregiver as opposed to allowing leave or part-time work. This however did not exempt those participants with qualifications from experiencing difficulties. The difference occurred with those participants who had access to additional support structures to assist with caring for the child.

For affluent and disadvantaged caregivers, the stress and concern for the sickly child was equal yet a difference occurred when considering monetary availability. For those participants that had access to money and support of others aiding in caring for the child, the reports of financial strain due to health related difficulties was still present yet not as desperate. Those with less access to resources noted intense struggle especially as the South African Care Dependency Grant (South African Government Services., 2013) and later (when the child is over 18 years) the acquisition of a Disability Grant (South African Government Services., 2013) is reported to not be enough to cover all the costs that are incurred.

As a result, many of the participants reported to have lost their jobs due to the need to care for the children (Lam and Mackenzie, 2002) with the inability to rely on grant money to supplement their income (South African Government Services., 2013). The participants noted that it was not always possible to arrange for someone to care for the child and could not afford to pay an additional caregiver. Thus once again, in most cases the responsibility of caring for the child lay on them, at the detriment of their job and financial well being. This in turn led to decreased ability to expose the child to the resources they require. This is

supported by the literature that notes that these children are often deprived of adequate healthcare, education, therapy and intervention strategies as well as assistive devices as a result of inadequate funds (Gcaza and Lorenzo, 2008, Lam and Mackenzie, 2002, Bross et al., 2008). The inability to perform continuous vocational pursuits coupled with the costs of health care was noted to be a strain on the caregiver. This, accompanied by the constant need for provision for the child's general needs as well as the demands from the rest of the family unit was considered the greatest stressors for the participants.

Behavioural challenges were noted by the participants as negative factors contributing to raising the child. This presented as the converse of the child's loving nature as seen in the positive aspects. This is evident in the research, whereby as the child grows and develops, negative behavioural manifestations occur (Silverman, 2007, Dykens, 2007, Pueschel et al., 1991). The most prominent as seen across the cultural and socio-economic backgrounds and supported by the literature was stubbornness (Menolascino, 1965, Pueschel et al., 1991). The participants agreed that the children were incapable of waiting, reasoning with them was not an option and when they refused to do something very little could persuade them otherwise. Many participants recalled the use of bribery, such as favourite food choices to coax the children into performing chores or behaving in a way that is more socially acceptable. Although this was considered a negative factor, the majority of the participants showed a good sense of humour and laughed throughout the recollection of their experiences. This was also likened to the behaviour of a typical child who is naughty yet with more intensity. This is possibly the way in which participants rationalize the behavior and aid themselves in coping with outbursts thus relating to their positive outlook when recalling the child's conduct.

As seen with the factors that contribute to the participants' positive experiences; negative family and community perceptions toward the child and caregiver impact their lives. This was supported by the research which reports that the attitudes of others affect the lives of caregivers (Rajh, 2005, Botha et al., 2006, Mhlanga, 2013). This is the case when the expectations of the child experienced by the family and community are not met (Rajh, 2005). Thus the family and community

feel a sense of disappointment and wish to shift blame and separate themselves from that which they do not understand (Rajh, 2005, Botha et al., 2006). In turn, literature states that prejudice and levels of abuse plague the life of the caregiver and child (Rajh, 2005, Botha et al., 2006, Lansdown, 2002).

Family reactions were specifically reported to be in terms of the partner or spouse and other children that the participant cares for. In some cases, participants recalled how their family unit disintegrated as a result of having a child with Down syndrome. Kaufman and Uhlenberg (1998) documented that families undergo stress and strain as a result of caring for a child with impairments, often resulting in separation of the family unit. As with the positive aspects of family reactions and support, the converse affects caregivers greatly. The relationships were reported to suffer due to the demands placed upon the caregiver and personal attitudes of the family members (Kaufman and Uhlenberg, 1998, Beresford et al., 2007). In the case of many of the participants and as seen in the literature, this often leads to families separating rather than unifying (Boyd, 2002).

Most prominent, according to many participants, were the reactions of the male partner or spouse, in their lives. It has been documented nationally and internationally that caring for a child with Down syndrome can either bring a couple together or drive them apart (Beresford et al., 2007, Kaufman and Uhlenberg, 1998, Boyd, 2002, Jakobsson et al., 2007, Naidoo et al., 2011). The presence of cultural influence within South Africa has been noted to sway decisions at times of partners uniting as mothers are at times blamed for the birth of the child (Rajh, 2005, Mhlanga, 2013).

It was described that once the child was born, in many cases; the father figure disowned the child with the caregiver attributing this to the fact that they did not have other occurrences of disability in the family. The men often blamed the women and reneged on their responsibility to care for the participant and the child by abandoning both mother and child (Lansdown, 2002). This was found to be the case across cultures within the study and can be qualified by other research studies conducted within South Africa (Lansdown, 2002, Botha et al., 2006, Jakobsson et al., 2007). This in turn added to the difficulties experienced by the

caregivers as they now had to cope with additional stressors as a single caregiver (Blacher and Baker, 2002).

As seen in the study by Lansdown (2002), men within an urban setting often attempt to escape the difficulties associated with the child, which was qualified by some of the participants. Whilst men from rural settings attempt to remove themselves from the negative attitudes of the community and their family members, which was qualified by many (Lansdown, 2002).

The participants noted to have often felt guilt and self-blame for having a child with Down syndrome. It is possible that these self-destructive feelings are at times exacerbated by the partners within their lives. As supported by literature and seen within the study, South African men often attribute the birth of a child with 'special needs' to curses or wrong-doings by the mother (Lansdown, 2002, Penn et al., 2010). This results in single-parent or caregiver households which greatly increases the demands and stresses experienced on the caregiver (Lansdown, 2002).

As previously reported, financial challenges surrounding the child's health and the demands of the child resulting in decreased vocational pursuits are a reality. In addition to this, difficulties in the participants' relationships were reported with regards to the child's care dependency grant payments. It was noted by many of the participants that their partners or spouses demanded money from them as they felt entitled to a portion of the care dependency grant. Some of the participants also felt that their partner or spouse was still in the relationship for the sole purpose of gaining through the child's care dependency grant. The participants reported feelings of sadness and resentment when discussing this as they expressed the importance of the use of the grant for schooling, hospital visits and saving for the child's future.

The demands placed upon the participants by their partners and financial issues were also exacerbated by the other children for whom they care. The responses of other children within the household were expressed to be an additional stressor. Majority of the participants noted a general sense of jealousy amongst the siblings

and other children living within the home of the child with Down syndrome. The participants reported that the other children have expressed feelings of decreased attention whereby they felt all the caregivers' attention is given to the child with Down syndrome (Beresford et al., 2007). Beresford et al (2007) supported this whereby the study noted that participants also recalled that the children felt as if the child with Down syndrome is treated differently. In this sense, the child with Down syndrome is given more leniency and is often spoilt by the caregiver (Beresford et al., 2007). This resulted in the caregivers having to divide their attention, explain in length the needs of the child with Down syndrome and try reduce the children's' perceptions of neglect (Beresford et al., 2007). This in itself requires increased amounts of energy and only serves to heighten the demands of the caregiver (Boyd, 2002, Gcaza and Lorenzo, 2008, Jakobsson et al., 2007).

In terms of community reactions, the positive attitudes have been noted with the accompanying assistance it has afforded the participants (*See the positive factors of raising the child with Down syndrome, pg 95*). Participants also described the negative aspects of their community. Majority of the rural participants (58.3% of the rural participants, 38.8% of the total participants), noted the negative effects the community attitudes have on them personally and raising the child. This was in contrast to the remainder of the rural participants and most of the urban participants which recalled mainly positive experiences. Different factors could be attributed to the divide in experiences, such as different communities in which the rural participants reside thus community members with differing attitudes; the personality type of the participants and what they will accept and what they consider offensive as well as the difference in the level of involvement of community members in rural versus urban settings (Swanson, 2007, Boyd, 2002). Participants noted that within rural communities members take an active interest in the lives of other members (Swanson, 2007, Sonn and Fisher, 1998). This could lead to communities supporting or rejecting the participants (Swanson, 2007, Rajh, 2005).

In terms of reported negative reactions, community reactions were reported to be unforgiving as a sense of ignorance and subsequent prejudice for what is considered 'abnormal' pervades (Lansdown, 2002, Rajh, 2005). Participants

expressed the extreme stigmatization that has been attached to them and the child as a result of the child's diagnosis (Lansdown, 2002). Participants noted that community members did not want to touch the child, have the child or the caregiver enter their house or for the child to play with their children. The participants spoke of the hurtful gossip and blatant shunning by the community as well as how cruel the other children could be to the child with Down syndrome. Due to the decreased understanding and the choice not to become educated, the caregivers and children have suffered at the hands of the judging public (Lansdown, 2002).

5.2.6 International versus National: A comparison

There is a notable difference between studies conducted internationally and the findings in this study along with other South African research, although it is limited. International literature presents findings that relate to the fact that although it is challenging caring for a child with special needs (Gcaza and Lorenzo, 2008), caregivers deem it as a stressor rather than a negative event (Hodapp, 2007). Furthermore, studies relate the birth of a child with Down syndrome and subsequent action of the family as adapting to the situation and problem solving as they would should they need to move house or change their vocation (Jakobsson et al., 2007). Research internationally states that families are no more affected or impacted by having a child with Down syndrome than those families who have typically developing children (Cunningham, 1996). Thus the viewpoint of international literature adopts a stance that implies caring for a child with Down syndrome is more manageable.

There are some similarities in the findings of this study such as caregivers reaching a level of acceptance and continuing with their lives as well as families uniting or separating as a result of the child. However, the severity of the situation nationally would appear to be elevated when compared to the international findings. This study explored the hardships, cultural influences, prejudices and negative attitudes along with the positive aspects and outcomes.

The reality within KwaZulu-Natal is that often families do not unite; they struggle with decreased finances and lack of support which results in their inability to

problem solve and view it as a stress factor (Botha et al., 2006, Engelbrecht et al., 2001, Jakobsson et al., 2007). These elements have been noted to add increased levels of strain and stress in the lives of the caregivers. Although many have come to accept it as daily life and would not change the situation, they have not spared any detail on the challenges that raising a child with Down syndrome poses.

It is possible that the infrastructure and availability of health resources internationally play a large role in the perceptions of caring for a child with Down syndrome.

However recent a recent study abroad states that due to a child with Down syndrome being considered a greater burden of care (McGrath et al., 2011), it results in difficulties as seen in this country. Health challenges are more prominent than other children with special needs and typically developing children thus there is an increase in the demand for care (McGrath et al., 2011). Furthermore, this study refutes previous literature that reports that parents adapt well and do not experience any more difficulty than families without a Down syndrome child (McGrath et al., 2011).

Thus it appears that availability of resources and the family's ability to cope cannot be accurately compared between first world and third world countries. Those experiencing poverty of resources present with similar needs and challenges whilst those with availability of support, healthcare and monetary security experience more stable environments and this appears to be the case worldwide.

5.2.7 Advice to other caregivers (*See objective IV, pg 4*)

The participants all felt that they had a message to share with other caregivers either beginning to care for a child with Down syndrome or even to those who have been caring for the child. These were the subjective experiences that the participants felt had assisted them as well improved their lives and could possibly do the same for others.

There was a general consensus in terms of exposing the child to the public. Caregivers across cultures and socio-economic standings expressed that although

the child is 'different' from typically developing children; they are still that caregiver's child, biological or otherwise. They stressed the need to expose these children in the community in order to integrate the child into society as well as to educate the public. They stated that caregivers should try not to let negative comments or perceptions influence them and instead focus on the positive aspects of the child.

Support systems were a large factor whereby participants repeatedly reported the necessity for support groups; family members; community members; friends and the like who will be able to assist . Participants went as far to state that it is virtually impossible to care for the child entirely alone and that help should be sought when necessary. This was related in terms of gaining knowledge; interacting with other caregivers, learning from each other and being able to take a break from the demands of caring for the child (Rajh, 2005, Boyd, 2002).

Their message also encompassed the need for the caregiver to accept the child and not to underestimate their potential. They noted that the child should be educated and assisted to learn as although they are slower to develop, they are able to achieve. Literature supports the child's ability to be trained and learn information, although they need longer periods and the execution is not as skilled, they should be afforded the opportunity (Fidler and Nadel, 2007, Ward, 2002). This related to the participants expressing the need for the public to be further educated on the topic of Down syndrome. In this sense, the participants expressed the need for society to reduce their level of ignorance and for individuals to take part in aiding these children, be it in creating special needs schools, sheltered workshops, offering employment or even spreading awareness.

5.3 Summary

Various aspects were discussed in the above chapter including the participants' initial reactions; feelings toward the child; positive and negative factors as well as the dynamics of relationships that are affected as a result of caring for the child. The similarities and differences of international and national literature were compared including the factors that specifically impact participants within a KwaZulu-Natal context. The participants' advice to other caregivers was noted to

ensure that their subjective experience adds value to the study and to assist in achieving the aim of informing and guiding the health profession when offering intervention to such individuals.

CHAPTER SIX

CONCLUSION

6.1 Introduction

This chapter highlights the limitations of the study, the recommendations for future studies, the significance of this study as well as the implications for research and practice.

6.2 Limitations

The geographical locations of the study could have encompassed a larger area and could have included further regions within KwaZulu-Natal. This was however limited by the time frame and the available resources. The sample size was limited due to decreased time frame limitations thus greater sample groups could not be utilized for this study. The focus groups and interviews had to be separated according to predominantly English and predominantly isiZulu speakers. Although this was conducted to allow for a greater level of comfort and expression, it still posed a limitation. This resulted in homogenous groups being conducted which may have cultural implications or a level of bias. The study predominantly included females which was not a prerequisite but rather due to a larger number of females consenting to participation in the study. It is possible that females were interested in participating due to the active role they play in the lives of the children when compared to the male or father figure who is often occupied by vocational pursuits or at times absent from the family unit (*See Discussion, The negative factors of raising the child with Down syndrome, pg 97*). This limited gender differences and promoted gender bias. A limitation was also the decreased interest of individuals when asked to participate.

6.3 Significance of the study

As limited research has been conducted on the perceptions of raising a child with Down syndrome within KwaZulu-Natal, the study facilitated greater exploration and insights into the phenomenon that encompasses raising a child with Down syndrome. The study allowed for the subjective experience, perceptions, attitudes and coping strategies (*See objectives I-IV, pg 4 & Research question, pg 4*) of the

diverse caregivers within the province to be explored through the use of an interpretive phenomenological framework (van Manen, 2007). This in turn allows for information to be gathered within a cultural context in order to supplement the knowledge base of KwaZulu-Natal.

Through the acquisition of understanding, it may assist with integrating children with Down syndrome into society through a more positive outlook of these children and a decrease in the underestimation of their abilities. As negative attitudes are a reality nationally and internationally (Botha et al., 2006, Lansdown, 2002, Boyd, 2002, Ward, 2002, Jakobsson et al., 2007, Kaufman and Uhlenberg, 1998, Gcaza and Lorenzo, 2008), there is the hope that improved insights will assist in decreasing the cases of neglect and promote acceptance of these children by the caregivers themselves, their families and the public. In addition, improving health professionals' understanding of the dynamics surrounding caring for a child with Down syndrome will aid in providing comprehensive intervention that adopts a psychosocial stand-point and thus improve the quality of life for the caregiver and child. This would benefit Occupational therapists who aim to provide a holistic approach when planning and implementing therapy as well as other health professionals who utilize the psychosocial model with clients.

The study explores the emotions of the caregivers including the challenges; benefits; barriers and limitations of caring for the child. It provides information on the interpersonal relationships of caregivers and their family; community and support systems. In this way the study assists as a platform in order for these caregivers to voice their opinions, spread awareness to other caregivers and the public as well as share a firsthand account of their experiences.

The findings also highlight the methods utilized by participants in order to cope or manage with caring for the child. These are beneficial for other caregivers who are either currently raising a child with Down syndrome or those who are beginning to care for a child. It is also useful for health professionals who may suggest these methods to clients as means to improve their experience and quality of life. In addition, caregivers also provided advice to each other which allow the findings to aid other individuals through suggestions that have been found to be effective. In

these ways the study may be used to assist others rather than merely state facts and results.

The aim of the study was to utilize the information gathered in order to guide health professionals (See *Aim, pg 4*). Thus the study will assist in promoting empathy of health professionals when providing intervention to these caregivers. In this manner it will aid in therapy planning, implementation of therapy aims and improve the caregivers' quality of life through more informed service delivery.

6.4 Recommendations

- I. The geographical location of future studies could utilize a larger vicinity of KwaZulu-Natal to collect data and obtain participants as this would allow for a more diverse study.
- II. The age groups of the caregiver participants utilized could include varying age groups of children with Down syndrome which would allow the researcher to draw multiple comparisons based on developmental stages.
- III. Gender comparisons of the children with Down syndrome could be drawn to address any similarities or differences as well as incidence.
- IV. The highlighting of the various types of Down syndrome could allow for comparisons and the impact on the caregivers to be drawn. This will allow for the functional differences and therefore the impact to be explored.
- V. Conducting the study utilizing fathers or male caregivers as this sample group would allow for diversity of the study as this study predominantly included females. This would allow for a varying perspective and help to inform those studies that were previously performed within South Africa.
- VI. Drawing comparisons between rural and urban communities to determine whether there are differences in opinion and whether affluence plays a role in their perceptions.
- VII. To gain insight into the role that support systems within South Africa play in order to raise awareness of these groups and the impact they may have on the population group.
- VIII. To research the benefits of early intervention therapy with a multidisciplinary team in the development of a child with Down syndrome.

- IX. To ascertain the effectiveness of Down syndrome workshops within the community setting. This is in order to determine whether it is a viable method to raise awareness of Down syndrome; the etiology; therapy options; the experience of raising the child and the like.
- X. To explore the effect of initial support for caregivers of children with Down syndrome to determine whether there is a significant impact to their attitude and ability to cope.

6.5 Conclusion

As the participants overcame the initial, predominantly emotional reactions and sought information in the form of: understanding the diagnosis; etiology; support groups and opportunities to interact with other caregivers, they reported that their perceptions became more positive. This was enhanced by their personal growth and the loving nature of the child. Crucial steps were taken by participants whereby there was a shift from passivity to the acquisition of knowledge and the inclusion of community and family involvement rather than isolation.

An improved experience of raising the child was reported when family and community reactions were positive. The additional offering of support and care for the child by family and community members was described to improve the caregivers' quality of life. Conversely, negative factors were also discussed in terms of the child's erratic health conditions, the financial implications this posed and as a result the strain it caused for the caregivers' interpersonal relationships. Negative family and community experiences were noted, in terms of attitudes and behaviours toward the child and caregiver. Family issues predominantly surrounded spouses or partners and other children being raised within the household, often resulting in separation of the family unit. The child's behavioural difficulties, specifically stubbornness and the inability to compromise was reported, however it was not considered a serious contributing factor.

It was notable that there appeared to be no significant discrepancy of findings when comparing participant experiences worldwide. Although first world countries

possess more developed infrastructure and support systems, similar challenges were noted in the South African context.

The participants acknowledged challenges and discussed these in detail; however, there was a pervading optimism amongst the participants. They offered advice to other caregivers, expressing the need for raising awareness by exposing the child to the public, accepting them for who they are and never underestimating the child's potential.

The overall message derived from these participants was one of love and appreciation for their child with Down syndrome. According to the participants, no challenge is too great when you accept the child and treat him or her as any other typical child. Most participants expressed that although support systems greatly improved their experience and that of their child, they would take on the task of raising their child without support, if necessary, because of their unshakable love for and commitment to the wellbeing of their child with Down Syndrome.

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Appendix 1

Explaining the study to possible survey participants (English)

THE EXPERIENCE OF RAISING A CHILD WITH DOWN SYNDROME: PERCEPTIONS OF CAREGIVERS IN KWAZULU-NATAL

The purpose of the study is therefore to explore the experiences of these caregivers within the context of Kwa-Zulu Natal.

As found by the researcher, there is limited information within South Africa especially when considering what it is like to care for a child with Down syndrome. By gaining this information it will allow for health professionals to better understand the experiences of these caregivers and ensure that they are sensitive to them when providing intervention.

You were identified as one of the participants as you fit the criteria of the study which states that all participants are to be:

1. Members of The Down syndrome Association KwaZulu-Natal
2. Individuals that attend the genetic clinics that The Down syndrome Association KwaZulu-Natal includes in their outreach program namely: King Edward Home Program Clinic and Prince Mshiyeni Home Program.
3. Individuals that attend the hospitals that The Down syndrome Association KwaZulu-Natal includes in their outreach program namely: Inkosi Albert Luthuli Central Hospital, Phoenix Assessment and Therapy Centre, Mahatma Gandhi Hospital.
4. The child that the caregivers raise must have a formal diagnosis of Down syndrome.
5. All participants are to reside within KwaZulu-Natal
6. All participants are to speak English or isiZulu as their home language or be bilingual

The attached survey shows a range of questions that are easy to fill in and only require that you tick the appropriate answer (which will take approximately 15 minutes). There is a section containing questions relating to race, age, gender and so on. These are only to further assist in the results that are obtained. As a participant you are only asked to complete the survey and return it to the association/ researcher (depending what is agreed upon) within the period of a month.

As you will see, the survey does not include any names or identification numbers, thus it is completely anonymous.

All information gathered from the survey will only be used for the purpose of the study and all documentation will be kept safe by the researcher and destroyed after a period of 5 years by shredding as per ethical guidelines.

As an individual, you have the right to refuse to participate in this study. Furthermore you may agree to participate and later withdraw from the study without any consequences. You may choose not to partake in the study as the choice is voluntary and you may choose to leave the study at any point without having to provide a reason to the researcher.

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Appendix 2

Explaining the study to possible survey participants (isiZulu)

OBHEKANA NAKHO EKUKHULISENI UMNTWANA ONE-DOWN SYNDROME: IMIBONO YABANAKEKELI KWAZULU -NATALI

The purpose of the study is therefore to explore the experiences of these caregivers within the context of Kwa-Zulu Natal.

Njengokuthola komcwaningi, kunolwazi oluncane eNingizimu Afrika ikakhulukazi mayelana nokuthi kunjani ukunakekela umntwana one-Downs syndrome. Ngokutholakala kwalolu lwazi kuyosizakala abasebenzi bezempilo ukuba baqonde okubhekene nabanakekeli futhi kuqinisekise nokuthi uma besebenzisana nabo bayoba nozwelo.

Wena uhlonzwe njengomunye wabangazibandakanya njengoba uhlangabezana nezimfuno zalolu cwango nezingukuthi:

1. Uyilungu leDowns syndrome South Africa
2. Labo abahambela imitholampilo yolibofuzo efakwe ngabakwa-Downs Syndrome South Africa ezinhlelweni zazo zokufinyelela empakathini :okuyi-King Edward Home Programme Clinic kanye ne-Prince Mshiyeni Home Program.
3. Abahamba izibhedlela ezifakwe ngabakwa-Downs Syndrome South Africa ohlelweni lwabo lokufinyelela empakathini: okuyi-Inkosi Albert Luthuli Central Hospital, i-Phoenix Assessment and Therapy Centre kanye ne-Mahatma Gandhi Hospital
4. Umntwana one-Downs Syndrome uzoba nohlobo iTrisomy 21.
5. Bonke abazibandakanyayo kufanele babe ngabahlala KwaZulu Natali.
6. Bonke abazibandakanyayo kufanele bakhulume isiNgisi kumbe isiZulu njengolimi lwabo lwasekhaya noma-ke babe ngabalimimbili.

Leli phepha-mibuzo elihambisana naleli linemibuzo ehlukehukene nokulula ukuyiphendula futhi idinga nje ukuthi uthikhe impendulo efanele (okuzokuthatha isikhathi esiyimizuzu ephakathi kuka 15-30). Kukhona isigaba esinemibuzo emayelana nebala, iminyaka yobudala, ubulili nokunye. Lokhu kwenzelwe nje ukulekelela emiphumeleni engase itholakale. Njengoyingxenye ucelwa kuphela ukuba ugcwalise leli phepha-mbuzo bese ulibuyiselakusosesheni/kumcwaningi (kuncike kokuvunyelwene ngakho) esikhathini esingangenyanga.

Njengalokhu ubona iphepha-mibuzo kalinabandakanyi amagama kanye nezinombolo zomazisi, ngalokho-ke kusho ukuthi kalihlonzi gama la muntu.

Lonke ulwazi oluqoqwe ngamaphepha-mibuzo luyosetshenziselwa izinhloso zocwaningo kuphela futhi umcwaningi uyolunakekele bese elichitha ngemva kweminyaka emihlanu ngokuwagaya lawo maphepha njengokudingwa yimigomo yokuziphatha kwabacaningi.

Wena unguwe nje unelungelo lokulandula ukuba yingxenye yalolu cwaningo. Ngaphezu kwalokho ungavuma ukuba yingxenye bese uhoxa ngemva kokuhamba kwesikhathi ngale kwezizathu. Ungakhetha ukungazibandakanyi nocwaningo njengoba vele kungukuvolontiya futhi ungakhetha ukuhoxa noma kunini ngale kokunikezela ngezizathu zalokho kumcwaningi.

Ngeminye iminingwana ungathintana nalaba:

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Appendix 3

Explaining the study to possible focus group participants

THE EXPERIENCE OF RAISING A CHILD WITH DOWN SYNDROME: PERCEPTIONS OF CAREGIVERS IN KWAZULU-NATAL

The purpose of the study is therefore to explore the experiences of these caregivers within the context of Kwa-Zulu Natal.

As found by the researcher, there is limited information within South Africa especially when considering what it is like to care for a child with Down syndrome. By gaining this information it will allow for health professionals to better understand the experiences of these caregivers and ensure that they are sensitive to them when providing intervention.

The use of a focus group allows the researcher to ask questions to a group of people that all have or are currently caring for a child with Down syndrome. The environment is not one that is intrusive but rather supportive to allow the individuals to speak freely about their own personal experiences. A handout containing information such as race, age, gender and so on will be given out by the researcher to be completed by the participants. These are only to further assist in the results that are obtained.

The criteria used to select possible participants are:

1. The participants must not have taken part in the survey of phase one.
2. Are to be either members of The Down syndrome Association KwaZulu-Natal or individuals who attend the outreach program as stated in point 2 above.
3. All the Caregivers have to be or have cared for the child with Down syndrome for at least 5 years to ensure that they have enough subjective experience in order to report and offer their experiences.
4. The child that the caregivers raise must have a formal diagnosis of Down syndrome.
5. The child with Down syndrome is to be within the age of 5-11

The researcher will use a digital recorder to record all that is said within the group. This information will only be utilized for the study and will remain safely in the researcher's possession.

The individual's information that is shared will remain confidential and the data will only be used for the purpose of the study. The individual's true identity will not be used in the study but rather a number/code will be assigned to represent them.

The individuals may refuse to participate in the study and are able to withdraw from the study at any point without any consequences. It is also important to note that through the conduction of my study there will be no known or anticipated risk to any of the participants involved. The researcher will offer debriefing should any person need this to help them to deal with any emotional distress. Should anyone feel distressed they will be able to take a break from the focus group, chose to stop speaking until they feel comfortable again or withdraw from the study. The researcher will also refer any participant that requires it to a counselor.

It must be noted that all transport costs will be paid for by the researcher. Thus should anyone need to take public transport, the cost will be covered. No money will be paid by any participant for engaging in this study.

By gathering this information there is also the chance to assist other caregivers in terms of support, ways to cope and to show them that they are not alone.

Contact Details:

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Qualifications: (BOT (UDW), MOT (UKZN), CAMAG (ABIME)

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Appendix 4

Explaining the study to possible focus group participants (isiZulu)

OBHEKANA NAKHO EKUKHULISENI UMNTWANA ONE-DOWN SYNDROME:

IMIBONO YABANAKEKELI KWAZULU -NATALI

Ngakho inhloso yalolu cwaningo kufanele kube ngukubhekisisa okubhekana nabanakekeli ngokuba kwabo KwaZulu Natali.

Njengoba kwatholwa ngumcwaningi, kunolwazi oluncane eNingizimu Afrika ikakhulukazi uma kubhekwa ubunjalo bomsebenzi wokunakekela umntwana one-Down Syndrome.

Ngokutholakala kwalolu lwazi kuzonikeza ochwepheshe kwezempilo ithuba lokuqondisisa okubhekana nalaba nakekeli ukuze benze isiqiniseko sokuba baba nozwelo lapho bengenolela ezimweni zabagulayo.

Ukusetshenziswa kweqembu labaqoqelwe ukucwaninga kuvumela umcwaningi ukuba abuze imibuzo kuleli qembu labantu abaseke banakekela kumbe kumanje banakekela abantwana abane-Down syndrome. Isimo sokubuzwa kwemibuzo kasinangcindezi kodwa siyoba yindlela onokuxhasana nokuzwelana ukuze labo ababuzwayo beyokwazi ukukhuluma ngokukhululeka ngezinto asebeke babhekana nazo ngqo bona uqobo. Umcwaningi uyonikeza iphepha-mibuzo kuleli qembu, leli phepha lizobe libuza mayelana nebala, ubudala, ubulili nokunye futhi kudingeka ligcwaliswe ngabazibandakanye nocwaningo. Lokhu kuyosiza-nje emiphumelweni eyotholakala.

Uhlaka olusetshenziwe ukuqoka abantu abangase bazibandakanye:

1. Abazibandakanyayo kufanele kube ngabangakaze babe yingxenywe yocwaningo lwesigaba sokuqala
2. Kufanele babe ngamalungu e-The Down syndrome Association KwaZulu-Natal noma babe ngabantu abahamba izinhlelo njengoba kubalulwe ephuzwini lesibili.
3. Bonke abanakekeli kufanele babe ngabanakekela abantwana abane-Down syndrome noma babe ngabake banakekela abantwana abanjalo okungenani iminyaka emihlanu ukuze kuqinisekise ukuba banolwazi olwanele lokubhekana nalesi simo funa bakwazi ukwanbelana ngezinsalele ababhekana nazo.
4. Umntwana one-Down Syndrome kufanele abe nohlobo lwe-Trisomy 21
5. Umntwana one-Down Syndrome kufanele abe neminyaka yobudala ephakathi kuka 5 no 11.

Umcwaningi uyosebenzisa isiqophi ukuze aqophe yonke inkulumo yeqembu. Lolu lwazi luyosetshenziselwa ucwaningo futhi loyohlala luphephile kumcwaningi.

Ulwazi olukhulunywe ngumuntu luyohlala luyisifuba futhi ulwazi lolo luyosetshenziselwa ucwaningo kuphela. Umuntu akayukohlonzwa ngegama ocwaningweni kodwa kuyosetshenziswa inombolo/ikhodi ayoyinikwa ukuze kube yiyo emela igama lakhe. Abantu bangalandula ukuzibandkanya nocwaningo futhi bangakwazi ukuhoxa ocwaningeni noma kunini ngale kwezizathu.

Kubalulekile ukuba kwazeke ukuthi ngesikhathi kuqhutshwa ucwaningo lwami akuyukuba nabungozi obulindelekile nokwazekayo kulabo abazibandakanya nalo. Umcwaningi uyokuba nezingxoxo zokukhuthaza kulabo abazingayo ukuze basizakale ekubhekaneni nengcindezi yemizwa yabo. Uma kukhona ozizwa enesinxo bayokwazi ukuthatha ikhefu eqenjini, bakhethe ukuma ukukhuluma kuze kube sebekulungele lokhu kumbe bangahoxa nasocwaningweni. Umcwaningi uyodlulisela kumeluleki labo abakudingayo ukwelulekwa.

Kufanele kwazeke futhi ukuthi zonke izindleko zokugibela ziyothwalwa ngumcwaningi. Ngalokhu-ke uma kukhona odinga ukusebenzisa izithuthi-mphakathi, izindleko zakhe ziyohlizekwa. Akukho mali eyokhokhwa ngozibandakanyayo ngokuba yingxenye yocwaningo

Ngokuqoqwa kwalolu lwazi kungenzeke kusizakale abanyeabanakekeli ikakhulukazi ngokuxhaswa, ngezindlela zokunqoba izinselele nokubabonisa futhi ukuba kababodwa.

Iminingwane yokuxhumana :

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Ihhovisi Lezocwaningo:

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Appendix 5

Profile questions for the focus group (English)

CAREGIVER INFORMATION:

Caregiver's age: _____

- Caregiver's race:
- African
 - White
 - Indian
 - Coloured
 - Other (Please specify)
-
-

- Caregiver's gender
- Male
 - Female

- My home language
- English
 - isiZulu
 - Other (Please specify)
-
-

CHILD INFORMATION:

Child's age: _____

- Child's race:
- African
 - White
 - Indian
 - Coloured
 - Other (Please specify)
-
-

- Child's gender
- Male
 - Female

- Child's type of Down syndrome:
- Trisomy 21
 - Translocation
 - Mosaic
 - I do not know

Appendix 6

Profile questions for the focus group (isiZulu)

ULWAZI NGOMNAKEKELI:

Iminyaka yobudala yomnakekeli: _____

- Ibala lomnakekeli:
- Mnyama
 - Mhlophe
 - UmNdiya
 - Ikhiladi
 - Okunye (Sicela ukugagule)
-

- Ubulili bomnakekeli
- Owesilisa
 - Owesifazane

- Ulimi lwami lwasekhaya
- isiNgisi
 - isiZulu
 - Olunye (Sicela ukugagule)
-

ULWAZI NGOMNTWANA:

Iminyaka yobudala yomntwana: _____

- Ibala lomntwaa:
- Mnyama
 - Mhlophe
 - UmNdiya
 - Ikhiladi
 - Okunye (Sicela ukugagule)
-

- Ubulili bomntwana
- Owesilisa
 - Owesifazane

Uhlobo lwe-Down Syndrome emntwaneni:

- Trisomy 21
- Translocation
- Mosaic
- Angazi

Appendix 7

Proposed Survey (English)

QUESTION 1: BIOGRAPHICAL

1. I am

- Male
- Female

2. I am

- African
 - White
 - Indian
 - Coloured
 - Asian
 - Other (Please Specify)
-
-

3. My home language is

- English
 - isiZulu
 - Other (Please Specify)
-
-

4. The child that I care for is

- Less than 5 years
- 5-10 years
- 11-15 years
- Older than 15 years

5. The child that I care for is

- Male
- Female

6. The child that I care for has been diagnosed with Down syndrome type

- Trisomy 21
- Translocation
- Mosaic
- I do not know

7. The area where I live is

- A township
 - An informal settlement
 - A city/town
 - Other (**Please Specify**)
-
-

8. I am the only caregiver

- Yes
 - No (**please state who else cares for the child**)
-
-

9. How long have you been caring for the child?

- Less than 5 years
- 5-10 years
- 11-15 years
- More than 15 years

10. I am the child's

- Biological parent
 - Guardian
 - Sibling (brother/sister)
 - Family member
 - Caregiver but I am not physically related to the child
 - Other (**Please specify**)
-
-

QUESTION 2: EXPERIENCES

Please indicate which answer applies (**please tick only ONE answer FOR EACH QUESTION**) **ANSWER ALL THE QUESTIONS**

		Yes	No	I don't know	Not applicable
1	The doctor/nurse told me about Down syndrome				
2	I understand how a child gets Down syndrome				
3	I knew that the child would have special needs when he/she was born.				
4	I knew that there would be				

	challenges when raising the child				
5	Down syndrome can be cured				
6	I feel my family has accepted that the child has down syndrome				
7	I feel I have experienced problems in my family because of the child with Down syndrome				
8	I feel my community has accepted that the child has Down syndrome				
9	I feel my community treat me differently because of the child with Down syndrome				
10	My community helps me raise the child with Down syndrome				
11	I feel other children accept the child and play with him/her				
12	I feel the child has been treated badly by other children because of the Down syndrome				
13	When people see the child with Down syndrome, they stare at him/her				
14	When people see the child with Down syndrome, they choose not to be around him/her				
15	When people see the child with Down syndrome, they ask questions about him/her				
16	I was aware of therapy options when the child was small				
17	I know what therapy options are now				
18	The child has access to the resources (financial, support, therapy) that he/she needs eg: there is enough money for therapy/ transport to hospital				
19	I know of other caregivers of children with Down syndrome				
20	I know about support groups for Down syndrome				
21	Caring for the child has added stress to my life. It has been difficult caring for the child				
22	I spend most of my time caring for the child				
23	The child has health problems/ is sick a lot because of Down syndrome				
24	I have learnt things about caring for the child that could help other				

	caregivers				
25	Raising a child with Down syndrome has been very challenging/ difficult				
26	Raising a child with Down syndrome has not been too difficult				
27	The child is affectionate and loving				
28	I am affectionate and loving with the child				

Please answer the following **ONLY** if you gave birth to the child

		Yes	No	I don't know	I don't remember
29	My pregnancy was normal (without any problems)				
30	I had problem/s during my pregnancy				
31	I had scans and tests during my pregnancy				
32	I was told before my child was born that he/she has Down syndrome				
33	I was glad I knew that my child has Down syndrome before he/she was born.				
34	I wish I had not been told about my child's Down syndrome before he/she was born				
35	I believe that it is my fault that the child has Down syndrome				

QUESTION 3: ATTITUDES

Please indicate which answer applies (**please tick only ONE answer FOR EACH QUESTION**) **ANSWER ALL THE QUESTIONS**

		Strongly agree	Agree	Neutral	Disagree	Strongly disagree
1	Knowing the child has Down syndrome changed the way I felt about the child					
2	I was afraid of what my family would say/do					
3	I was afraid of what my community would say/do					
4	I feel my community talk badly about the child					
5	I had to do research on Down syndrome					

QUESTION 4: CHALLENGES & COPING

Please indicate which answer applies (**please tick only ONE answer FOR EACH QUESTION**) **ANSWER ALL THE QUESTIONS**

		Always 95% of the time	Often 75% of the time	Sometimes 45% of the time	Rarely 25% of the time	Never 0% of the time
1	I feel happy with my life					
2	I am sad when I think of my life					
3	I feel hopeless about the future					
4	I cry easily					
5	I feel tired					
6	I feel I need to rest in the day					
7	I feel I need help from others					
8	I feel like the child is a burden					
9	I find great love/joy caring for the child					
10	I love the child the same as other children without Down syndrome					
11	It is stressful/ hard caring for the child					
12	I am able to cope with the demands of caring for the child					
13	My loved ones feel that I spend too much time with the child and not enough time with them					
14	My loved ones help me care for the child					
15	The child has behavioural problems such as tantrums, aggressive behavior, does not listen/follow instructions					

QUESTION 5: EMOTIONAL EXPERIENCES

Please indicate which answer/s apply (you may tick MORE THAN ONE answer)

1. Being told the child has Down syndrome made you feel...

Upset	Angry	Guilty	Happy	Anxious/ nervous	No difference
-------	-------	--------	-------	------------------	---------------

2. My understanding of Down syndrome was...

Limited	I had never heard of the name	I had heard of the name	I knew some information about it	I knew a lot of information about it	It confused me
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3. The child has Down syndrome because...

A curse/ upsetting the ancestors	I did something wrong	The child's mother did something wrong	The child's father did something wrong	It is a medical condition that happens	I do not know
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4. My feeling towards the child initially was...

Love	Disappointment	Happiness	Anxiety	Confusion	Indifferent
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5. Telling my family made me feel...

Anxious/ Nervous/ worried	Happiness/joy	Sadness	Mixed emotions (positive and negative)	Indifferent
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6. The thought of my community knowing made me feel...

Anxious/ Nervous/ worried	Happiness/joy	Sadness	Mixed emotions (positive and negative)	Indifferent
---------------------------	---------------	---------	--	-------------

7. I have experienced problems due to the child with...

My spouse (husband/ wife/ partner)	My other child/ children	My parent/ parents	Other family members – aunts, uncles etc	I have not experienced any problems – they have been supportive
------------------------------------	--------------------------	--------------------	--	---

8. In terms of therapy I knew...

None of the available options	basic therapy such as nurse/ doctor	I knew about other therapy eg: physiotherapy	I knew most of the options eg: physiotherapy, Speech therapy, Occupational Therapy	I know all of the available therapy options
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9. In terms of therapy I now know...

None of the available options	I knew basic therapy such as nurse/ doctor	I knew about other therapy eg: physiotherapy	I knew most of the options eg: physiotherapy, Speech therapy, Occupational Therapy	I know all of the available therapy options
-------------------------------	--	--	--	---

10. The resources that I am able to access are...

(Please tick the one/s that are applicable (**You may tick MORE THAN ONE**):

Money	Support from family	Support from my community	Support from other caregivers	Support from organizations
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11. Caring for the child makes me feel...

Joy/happiness	Drained and tired	Frustrated/resentful	A mixture of emotions (positive and negative)	Hopeless	Indifferent
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12. The child is able to do the following independently

Dress	Eat	Bath	Toilet	Groom such as brushing teeth	None of these
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Appendix 8

Proposed Survey (Coded)

Descriptive Survey:

THE EXPERIENCE OF RAISING A CHILD WITH DOWN SYNDROME: PERCEPTIONS OF CAREGIVERS IN KWAZULU-NATAL

Question 1: Biographical

1.1 I am

Male	1
Female	2

1.2 I am

African	1
White	2
Indian	3
Coloured	4
Asian	5
Other	6

1.3 My home language is

English	1
IsiZulu	2
Other	3

1.4 The child that I care for is

<5 years	1
5-10 years	2
11-15 years	3
>15 years	4

1.5 The child that I care for is

Male	1
Female	2

1.6 The child that I care for has been diagnosed with Down syndrome type

Trisomy 21	1
Translocation	2
Mosaic	3

	I do not know	4
1.7 The area where I live is	A township	1
	An Informal Settlement	2
	A city/town	3
	Other	4
1.8 I am the only caregiver	Yes	1
	No	2
1.9 How long have you been caring for the child	<5 years	1
	5-10 years	2
	11-15 years	3
	>15 years	4
1.10 I am the child's	Biological parent	1
	Other	2
	Sibling(brother/sister)	3
	Family member	4
	Caregiver but I am not physically related to the child	5
	Guardian	6

Question 2: Experiences

2.1 The doctor/nurse told me about Down syndrome	Yes	1
2.2 I understand how a child gets Down syndrome	No	2
2.3 I knew that the child would have special needs when he/she was born.		
2.4 I knew that there would be challenges when raising the child	I don't know	3
2.5 Down syndrome can be cured	Not applicable	4
2.6 I feel my family has accepted that the child has down syndrome		
2.7 I feel I have experienced problems in my family because of the child with Down syndrome		
2.8 I feel my community has accepted that the child has Down		

syndrome

2.9 I feel my community treat me differently because of the child with Down syndrome

2.10 My community helps me raise the child with Down syndrome

2.11 I feel other children accept the child and play with him/her

2.12 I feel the child has been treated badly by other children because of the Down syndrome

2.13 When people see the child with Down syndrome, they stare at him/her

2.14 When people see the child with Down syndrome, they choose not to be around him/her

2.15 When people see the child with Down syndrome, they ask questions about him/her

2.16 I was aware of therapy options when the child was small

2.17 I know what therapy options are now

2.18 The child has access to the resources (financial, support, therapy) that he/she needs

2.19 I know of other caregivers of children with Down syndrome

2. 20 I know about support groups for Down syndrome

2.21 Caring for the child has added stress to my life. It has been difficult caring for the child

2.22 I spend most of my time caring for the child

2.23 The child has health problems/ is sick a lot because of Down syndrome

2.24 I have learnt things about caring for the child that could help other caregivers

2.25 Raising a child with Down syndrome has been very challenging/ difficult

2.26 Raising a child with Down syndrome has not been too difficult

2.27 The child is affectionate and loving

2.28 I am affectionate and loving with the child

Answer only if you gave birth to the child

2.29. My pregnancy was normal (without any problems)

Yes	1
No	2
I don't know	3
Not applicable	4

- 2.30 I had problem/s during my pregnancy
- 2.31 I had scans and tests during my pregnancy
- 2.32 I was told before my child was born that he/she has Down syndrome
- 2.33 I was glad I knew that my child has Down syndrome before he/she was born.

Yes	1
No	2
I don't know	3
I don't remember	4
Not applicable	5

- 2.34 I wish I had not been told about my child's Down syndrome before he/she was born
- 2.35 I believe that it is my fault that the child has Down syndrome

Question 3: Attitudes

- 3.1 Knowing the child has Down syndrome changed the way I felt about the child
- 3.2 I was afraid of what my family would say/do
- 3.3 I was afraid of what my community would say/do
- 3.4 I feel my community talk badly about the child
- 3.5 I had to do research on Down syndrome

Strongly Agree 95%	1
Agree 75%	2
Neutral 0%	3
Disagree 75%	4
Strongly disagree 95%	5

Question 4: Challenges and Coping

- 4.1 I feel happy with my life
- 4.2 I am sad when I think of my life
- 4.3 I feel hopeless about the future
- 4.4 I cry easily
- 4.5 I feel tired
- 4.6 I feel I need to rest in the day
- 4.7 I feel I need help from others
- 4.8 I feel like the child is a burden
- 4.9 I find great love/joy caring for the child
- 4.10 I love the child the same as other children without Down

Always 95%	1
Often 75%	2
Sometime 45%	3
Rarely 25%	4
Never 0%	5

syndrome

4.11 It is stressful/ hard caring for the child

4.12 am able to cope with the demands of caring for the child

4.13 My loved ones feel that I spend too much time with the child and not enough time with them

4.14 My loved ones help me care for the child

4.15 the child has behavioural problems such as tantrums, aggressive behavior, does not listen/follow instructions

Question 5: Emotional Experiences

5.1 Being told the child has Down syndrome made you feel

Upset	1
Angry	2
Guilty	3
Happy	4
Anxious	5
No difference	6

5.2 My understanding of Down syndrome was

Limited	1
I had never heard	2
I had heard	3
I knew some info	4
I knew a lot	5
It confused me	6

5.3 The Child has Down syndrome because

Curse/upsetting ancestors	1
I did something wrong	2
The child's mother did something wrong	3
The child's father did something wrong	4
It is a medical condition that happens	5

I do not know	6
---------------	---

5.4 My feeling toward the child initially was

Love	1
Disappointment	2
Happiness	3
Anxiety	4
Confusion	5
Indifferent	6

5.5 Telling my family made me feel

Anxious	1
Happiness	2
Sadness	3
Mixed	4
Indifferent	5

5.6 The thought of my community knowing made me feel

Anxious	1
Happiness	2
Sadness	3
Mixed	4
Indifferent	5

5.7 I have experienced problems due to the child with

My spouse	1
Other child/ren	2
Parents	3
Other family	4
No problems	5

5.8 In terms of therapy I knew

No options	1
Basic therapy	2
More options	3
Most options	4
All options	5

5.9 In terms of therapy I now know

No options	1
Basic therapy	2
More options	3
Most options	4
All options	5

5.10 The resources I am able to access are (more than one answer)

Money	1
Family support	2
Comm support	3
Caregiver support	4
Organisations	5

5.11 Caring for the child makes me feel

Happiness	1
Tired	2
Frustrated	3
Mixture	4
Hopeless	5
Indifferent	6

5.12 The child is able to do the following independently

Dress	1
Eat	2
Bath	3
Toilet	4
Groom	5
None of these	6

Appendix 9

Proposed Focus group questions and Prompts

Question	Motivation for the Question
“What was your immediate reaction when discovering that the child has Down syndrome? “	<ul style="list-style-type: none"> • Probe guilt, blame, shame • Probe knowledge vs ignorance • What had to be explored/learnt • Feelings of sadness vs possible acceptance at this stage.
How would you describe your experiences of raising a child with Down syndrome?	<ul style="list-style-type: none"> • Probe positives and negatives (economics, culture, health, family stress) • Probe whether the child’s level of dependence plays a role
Do you think this has had an effect on the rest of your family and if so how/what?	<ul style="list-style-type: none"> • Probe feelings of love towards the child • Probe what other support structures are – neighbours, friends, teachers, community counsellor • Probe changes in roles, attitudes • Probe positive impact of the family on the child ie support and assistance
Describe how other people respond to you and the child.	<ul style="list-style-type: none"> • Probe community and public attitudes • Probe barriers, acceptance, culture
What advice could you give to other caregivers in the same or similar situation?	<ul style="list-style-type: none"> • Probe coping mechanisms • Overcoming stress

Appendix 10

Request for Permission from The Down syndrome Association KwaZulu-Natal (once ethical clearance has been granted)

ATT: The Down syndrome Association KwaZulu-Natal

Proposed topic:

**THE EXPERIENCE OF RAISING A CHILD WITH DOWN SYNDROME:
PERCEPTIONS OF CAREGIVERS IN KWAZULU-NATAL**

My name is Megan Barr (208506169) and I am currently engaging in my masters through the University of Kwazulu-Natal Westville. The topic of my study is stated above and I am waiting to be granted Ethical Clearance in order to conduct my study.

Through my research and subsequent literature review it has become apparent that there is limited research on Down syndrome in the South African context let alone within Kwazulu-Natal.

Through the conduction of my study I aim to obtain data in terms of the psychosocial and interpersonal dynamics that surround raising a child with Down syndrome. I endeavor to produce comprehensive results in order to allow for health professionals, caregivers and the public to gain an understanding into the lives of these caregivers. Through understanding health care professionals as well as society will be able to adopt an empathetic standing to ensure that both therapy and support in general are more holistic.

As per my proposal, I will run a **pilot focus group (with 4-5 participants)** to ensure that my questions are effective. I plan to send out a survey to participants in order to help guide the questions for my focus group. I am planning to distribute the **survey to approximately 50 plus** participants to ensure that I gain a wide range of responses. **Two focus groups (with 6-8 participants in each group)** will be run after that which will be organized by the researcher.

I would like to ask if you would be able to assist me with obtaining the participants for my study due to your wide access to a database. I hope to include those individuals that are part of the The Down syndrome Association KwaZulu-Natal outreach program at various KZN hospitals. This will allow for diverse findings.

In total I am hoping to have access to:

- Approximately 50 members for the survey
- A minimum of 16 participants for my focus group (pilot study included).

The inclusion criteria are as follows:

The following criteria is to be utilized when selecting participants for the survey

Proposed participants are to be:

1. Members of The Down syndrome Association KwaZulu-Natal
2. Individuals that attend the genetic clinics that The Down syndrome Association KwaZulu-Natal includes in their outreach program namely: King Edward Home Programme Clinic and Prince Mshyeni Home Program.
3. Individuals that attend the hospitals that The Down syndrome Association KwaZulu-Natal includes in their outreach program namely: Inkosi Albert Luthuli Central Hospital, Phoenix Assessment and Therapy Centre, Mahatma Gandhi Hospital.
4. The child that the caregivers raise must have a formal diagnosis of Down syndrome.
5. All participants are to reside within KwaZulu-Natal
6. All participants are to speak English or isiZulu as their home language or be bilingual

The following additional criteria will be used when selecting participants for the focus group:

1. The participants must not have taken part in the survey of phase one.
2. Are to be either members of The Down syndrome Association KwaZulu-Natal or individuals who attend the outreach program as stated in point 2 above.
3. All the Caregivers have to be or have cared for the child with Down syndrome for at least 5 years to ensure that they have enough subjective experience in order to report and offer their experiences.
4. The child that the caregivers raise must have a formal diagnosis of Down syndrome.
5. The child with Down syndrome is to be within the age of 5-11

I have taken measures to ensure anonymity of the participants and will ensure that the data collected will only be used for the purpose of the study. Thereafter it will be kept under lock and key for the required 5 year period. All electronic documentation will be password accessed and confidentiality will be maintained through provision of signed documents for both the researcher and the interpreter.

The purpose and outline of the study will be explained to the participants and their right to refuse or withdraw at any point without consequence will be explained. It is also important to note that through the conduction of my study there will be no known or anticipated risk to any of the participants involved.

I am more than willing to answer any further questions or concerns that you may have.

I look forward to conducting this study with the help and support of The Down syndrome Association KwaZulu-Natal.

Thanking you in anticipation,

Kind Regards,

M. Barr

Contact Details:

Researcher: M. Barr 084 840 4001 megz13@hotmail.com

Supervisor P.Naidoo 031 260 8258 naidoopg@ukzn.ac.za

Qualifications: (BOT (UDW), MOT (UKZN), CAMAG (ABIME)

Supervisor G. Rencken 031 260 7052 rencken@ukzn.ac.za

Qualifications: BOT (UP), MOT (UFS)

Research Office:

Postgraduate Officer: Phindile Nene 031 2608280 nenep1@ukzn.ac.za

Appendix 11

Iphepha-mibuzo elihlongozwayo (isiZulu)

IMIBUZO 1: UQOBO LWAKHO

1. Ngingumuntu

- Wesililisa
- Wesifazane

2. Ngingumuntu

- Omnyama
 - Omhlophe
 - Umndiya
 - Ikhiladi
 - Um-ashiya
 - Okunye (sicela ukugagule)
-
-

3. Ulimi lwami lwasekhaya

- isiNgisi
 - isiZulu
 - Okunye (sicela ukugagule)
-
-

4. Umntwana enginnakekelayo uneminyaka

- engaphansi kwemi-5
- emi-5-10
- eyi-11-15
- Engaphezu kweyi-15

5. Umntwana enginnakekelayo

- Ungowesilisa
- Ungowesifazane

6. Umntwana enginnakekelayo utholwe eneDown syndrome yohlobo lwe-

- Trisomy 21
- Translocation
- Mosaic

Angazi

7. Indawo engihlala kuyo

Yilokishi

Imijondolo

Idolobha

Okunye (sicela ukugagule)

8. Yimi kuphela umnakekeli womntwana

Yebo

Cha (yisho ukuthi ngubani omunye onakekela umntwana)

9. Usunesikhathi esingakanani unakekela umntwana?

Engaphansi kwemi-5

Iminyaka emi-5-10

Iminyaka eyi-11-15

Iminyaka engaphezu kweyi-15

10. Emntwaneni ngingu-

-Mzali wegazi.

-Mbheki

-Ngizalwa naye (umfowabo/udadewabo)

Ilunga lomndeni wakho.

Umnakekeli kodwa angihlobene ngegazi nomntwana.

Okunye (sicela ukugagule)

UMBUZO 2: OSUBHEKANE NAKHO

Sicela ubeke uphawu empendulweni okuyiyo (**Thikha okuKODWA embuzweni ngaMunye kuphela**) **PHENDULA YONKE IMIBUZO**

		Yebo	Cha	Angazi	Akukho okwenzekile
1	Udokotela/unesi ungitshelile ngeDowns syndrome.				
2	Ngियाqonda ukuthi umntwana				

	uyithola kanjani iDowns syndrome.				
3	Ngangazi ukuthi umntwana uzoba nezidingo ezikhethekile uma esezelwe				
4	Ngangazi ukuthi kuyoba nezinseselele uma sengimkhulisa umntwana				
5	IDown syndrome iyelapheka				
6	Ngibona ukuthi umndeni wami usukwamukele ukuthi umntwana une-Down syndrome.				
7	Ngibona ukuthi ngibhekane nezinkinga emndenini wami ngenxa yokuba umntwana ene-Down syndrome				
8	Ngibona ukuthi umphakathi wakithi usukwamukele ukuthi umntwana une-Down syndrome				
9	Ngibona sengathi umphakathi ungiphatha ngendlela ehlukele kwabanye ngenxa yokuba umntwana ene-Down syndrome.				
10	Umphakathi wakithi uyangisiza ukuba ngikhulise umntwana one-Down syndrome				
11	Ngibona ukuthi abanye abantwana bayamamukela umntwana futhi badlala naye				
12	Ngibona ukuthi umntwana uphathwa kabi ngabanye abantwana ngoba ene-Down syndrome				
13	Uma abantu bebona umntwana one-Down syndrome bayamgqolozela.				
14	Uma abantu bebona umntwana one-Down syndrome bakhetha ukuzisondezi kuye				
15	Uma abantu bebona umntwana one-Down syndrome babuza imibuzo ngaye.				
16	Nganginolwazi ngezinhelo zokusiza isimo ngesikhathi umntwana esemncane				
17	Manje sengiyazi ukuthi izinhlelo zokusiza isimo ziyini.				
18	Umntwana unazo izinsiza (imali, uxhaso, kanye nokwelashwa) azidingayo isib. Kukhona imali eyanele yokuba asizwe/yokuba				

	ahanjiswe esibhedlela				
19	Ngiyazi ngabanye abanakekeli babantwana abane-Down syndrome				
20	Ngiyazi ngamaqembu okuxhasana akhelwe abane-Down syndrome.				
21	Ukunakekela lo mntwana kungifakele isinxo. Kunzima ukumnakekela				
22	Ngichitha isikhathi sami esiningi nginakekela umntwana				
23	Umntwana unenkinga yezempilo/ugula njalo ngenxa yeDown syndrome				
24	Sengifunde okuningi ngokunakekela omntwana nokungasiza nabanye abanakekeli				
25	Ukukhulisa umntwana one-Down syndrome kube nezinselelo/nzima				
26	Ukukhulisa umntwana one-Down syndrome akunzima kakhulu				
27	Umntwana unobungani nothando				
28	Nginobungani nothando lomntwana				

Sicela uphendule okulandelayo KUPHELA uma umntwana azalwa nguwe

		Yebo	Cha	Angazi	Angikhu mbuli
29	Ukukhulelwa kwami kwakungokwejwayelekile (kwakungenzazingqinamba)				
30	Ngaba nezingqinamba ekukhululweni kwami				
31	Ngahlolwa ngathathwa nezithombe ngesikhathi ngikhulelwe				
32	Ngaziswa umntwana wami engakazalwa ukuthi une-Down syndrome				
33	Ngiyajabula ukuthi ngazi ukuba umntwana wami uyagula ngaphambi kokuba azalwe				
34	Ngifisa sengabe angizange ngitshelwe ukuba umntwana wami une-Down syndrome engakazalwa				
35	Ngikholwa ngukuthi kuliphutha lami ukuba umntwana uneDown syndrome.				

UMBUZO 4: ISIMO SOMQONDO

Sicela usho ukuthi yiyiphi impendulo ehambisana nesimo sakho (Sicela uthikhe impendulo eYODWA embuzweni NGAMUNYE) PHENDULA YONKE IMIBUZO

		Ngivuma ngokuqinisekile	Ngiyavuma	Ngimaphakathi	Kangivumi	Kangivumi impela
1	Ukwazi ukuthi umntwana une-Down syndrome kwangenza ngashintsha indlela engizizwa ngayo ngalo mntwana					
2	Ngangisaba ukuthi umndeni wami uzothini/uzokwenzani					
3	Ngangisaba ukuba umphakathi wakithi wawuzothini/wawuzokwenzani.					
4	Ngibona ukuthi umphakathi wakithi ukhuluma kabi ngomntwana					
5	Kwafanela ukuba ngenze uphenyo ngeDown syndrome					

UMBUZO 4: IZINSELELE KANYE NOKUPHILA NAZO

Sicela usho ukuthi yiyiphi impendulo ehambisana nesimo sakho (Sicela uthikhe impendulo eYODWA embuzweni NGAMUNYE) PHENDULA YONKE IMIBUZO

		Sonke isikhathi 95% wezikhathi	ngokuvamile 75% wezikhathi	Ngezinye izikhathi 45% wezikhathi	akuvamile 25% wezikhathi	Akukaze 0% wesikhathi
1	Ngiyayithokozela impilo yami					
2	Ngiyajabha uma ngicabanga ngempilo yami					
3	Ngizizwa ngiphelelwe yithemba ngekusasa					
4	Ngiyashesha ukukhala					
5	Ngizizwa ngikhathale					
6	Ngizizwa sengathi kufanele ngiphumule njalo maphakathi nosuku					

7	Ngizizwa sengathi ngidinga usizo kwabanye					
8	Ngibona sengathi umntwana ungumthwalo					
9	Ngithola ukuthokoza/uthando ekunakekeleni umntwana					
10	Ngiyamthanda umntwana njengabo bonke abanye abantwana abangenayo iDown syndrome					
11	Kuyinkathazo/kunzima ukukhulisa lo mntwana					
12	Ngiyakwazi ukumelana nezidingo zokukhulisa lo mntwana					
13	Engisondelene nabo babona sengathi ngichitha isikhathi esiningi nomntwana kunabo					
14	Abasondelene nami bayangisiza ukunakekela umntwana					
15	Umntwana unezingqinamba ngesimilo njengokushawoda, ulaka,akalaleli/ akenzi akutshelwayo					

UMBUZO 5: OBHEKANE NAKHO NGOKWEMIZWA

Sicela usho impendulo ehambisana nesimo sakho (ungathikha impendulo ENGAPHEZU KWEYODWA)

1. Ukwaziswa ukuthi umntwana uneDown syndrome kwakwenza wazizwa.....

Ucikekile	Uthukuthele	Unecala	Ujabule	Unexhala/ unovalo	ungenamahluko
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2. Ukuqonda kwami ngeDown syndrome kwaku.....

kuncane	Ngangingakaze ngilizwe ngisho	Ngangazi ngaleli gama	Kwakukhona ulwazi enganginalo	Nganginolwazi oluningi ngayo	Kwangiphica nje
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	leli gama		ngayo		
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3. Umntwana une-Down syndrome ngoba..

Yisichitho/ukudelela amadlozi	Kukhona okungalungile engakwenza	Umama womntwana wenza okungalungile	Umama womntwana wenza okungalungile	Yisimo sezempilo esenzekayo	Angazi
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4. Indlela engangizizwa ngayo ngomntwana ekuqaleni kwakuwu.....

Uthando	Ukuphoxeka	Ukujabula	uvalo	ukudideka	kungenamahluko
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5. Ukutshela umndeni wami kwangenza ngaba

Nganovalo/ngakhathazeka	nokujabula	nokujabha	Nemizwa exubene (emihle nemibi)	kwakungenamahluko
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6. Umcabango wokwazi ukuthi umphakathi uyazi kwangenza

Ngaba novalo/nokukhathazeka	Ngajabula	ngajabha	Ngaba nemizwa exubene (emihle nemibi)	Angaba namehluko
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7. Ngenxa yomntwana sengibe nezinkinga no

Nengishade naye(umyeni/inkosikazi/uphathina)	Nomunye umntwana wami/abantwana bami	Nomzali wami/abazali bami	Amanye amalunga omndeni (o-anti, omalume njll)	I have not experienced any problems – they have been suppre Angikaze ngibe nezinkinga - bebengixhasile
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8. Mayelana nosizo lwezokwelashwa benginalolu lwazi.....

Bengingazi ngezinsiza ezikhona	Bengazi ngosizo oluncane njengonesi/udokotela	Bengazi ngolunye usizo lokulapha isib: ifiziyotheraphi	Bengazi izindlela eziningi isib: fiziyotheraphi, isipishi theraphi, kanye ne-okhyupheshinali theraphi	Bengazi mayelana nazo zonke izindlela zokwelapha ezilusizo.
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9. Mayelana nosizo lokwelashwa sengiyazi manje.....

Lutho olukhona	Ngazi ngosizo nje njengodokotela nonesi	Ngiyazi ngolunye usizo lokulapha isib: ifiziyotheraphi	Ngazi izindlela eziningi isib: fiziyotheraphi, isipishi theraphi, kanye ne-okhyupheshinali theraphi	Ngiyazi mayelana nazo zonke izindlela zokwelapha ezilusizo.
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10. Izinsiza engikwaziyo ukuzithola yilezi.....

(Sicela uthikhe okuhambisana nawe (**Ungathika OKUNGAPHEZU KOKUKODWA**):

Imali	Ukuxhaswa ngumndeni	Uxhaso lomphakathi	Uxhaso lwabanye abanakekeli	Uxhaso oluvela ezinhlanganweni
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11. Ukunakekela umntwana kungenza ngizizwe.....

Ngijabulile	Ngicobekile futhi	Ngixakekile /ngizisola	Ngibe nemizwa exubene (emihle)	Ngiphelelwe yithemba	ngingenamahluko
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	ngikhathele		nemibi)		
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12. Umntwana uyakwazi ukwenza lokhu okulandelayo eyedwa

Ukugqoka	Ukudla	Ukugeza	Ukuya endlini encane	Ukuziqeqesha njengokuxubha	Akenzi lutho kulokhu
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Appendix 12

Proposed Focus group questions with the motivation

Question	Motivation for the Question
“What was your immediate reaction when discovering that the child has Down syndrome? “	“The challenges of parenthood are intensified by the experience of having a child with special needs,”(Ainbinder et al., 1998a).
How would you describe your experiences of raising a child with Down syndrome?	
Do you think this has had an effect on the rest of your family and if so how/what?	Relationships within the family, including those of the parents, often suffer (Kaufman and Uhlenberg, 1998).
Describe how other people respond to you and the child.	Within South Africa, individuals who are not considered the norm are often viewed in a negative light (Botha et al., 2006).
What advice could you give to other caregivers in the same or similar situation?	‘Parent to parent help’ which denotes to one parent in a similar or the same situation offering support to each other encourages sharing of experiences as there is something that they share in common, which in turn allows for common understanding, support and allows for strength to be drawn,(Ainbinder et al., 1998b).

Appendix 13

Proposed Focus group questions (isiZulu)

Imibuzo ehlongozwayo yeqoqo elididiyelelwe ukucwaninga:

Imibuzo
“Yini eyokuqala eyakufikela ngesikhathi uthola ukuthi umntwana une-Downs syndrome?”
Ungasichaza kanjani isikhathi sakho ukhulisa umntwana one-Downs syndrome?
Ucabanga ukuthi lokhu kube nomthelela kuwo wonke umndeni wakho futhi uma kunjalo kube nomthelela onjani/muni?
Ake uchaze indlela abantu abanithatha ngayo wena nomntwana.
Ungabeluleka uthini abanye abanakekeli abasesimweni esifana nesakho?

Qaphela: Imibuzo engenhla izokuba yisibonakaliso ukuze uthole ukuthi umcwaningi uzobuza hlobo luni lwemibuzo. Imibuzo ingashintsha kancane ngenxa yokuthi iqembu lizobe lixoxa

Appendix 14

Nvivo 10 Node report

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Experiencing of raising a child with DS

Name	Description	Hierarchical Name	Number Of Coding References
Advice to other caregivers	The experience that caregivers have gained through raising a child with Down syndrome that would be beneficial to other caregivers caring for a child with Down syndrome.	Nodes\\Advice to other caregivers	56
Coping mechanisms	The strategies that caregivers utilize to cope and manage with caring for a child with Down syndrome. Includes tips and tricks to making it through day to day life	Nodes\\Advice to other caregivers\Coping mechanisms	3
Effect on the family	The impact that caring for a child with Down syndrome has had on the family - spouses, siblings, extended family. Positive and negative aspects as well as general family feelings towards the child.	Nodes\\Effect on the family	5
Men or fathers	Support versus neglect of the men or fathers in the lives of the caregivers and children.	Nodes\\Effect on the family\Men or fathers	31
Negative	Aspects that affect the family in a negative way eg: too much attention to the child with Down syndrome leading to feelings of jealousy	Nodes\\Effect on the family\Negative	32
Personal growth as a caregiver	Knowledge and strengths gained as a result of caring for the child with Down syndrome. What caregivers have personally learned about themselves and traits they have obtained or learned as a result of casring for the child	Nodes\\Effect on the family\Personal growth as a caregiver	10
Positive	The effect that caring for the child with Down syndrome has had on the family. Eg: Family uniting to care for the child. The good aspects that have resulted as a result of caring for the child.	Nodes\\Effect on the family\Positive	15
Experience of raising the child	Positive and negative aspects of caring for a child with Down syndrome. What is it really like? Challenges versus benefits.	Nodes\\Experience of raising the child	274
Child level of dependence	Dependence versus independence - does it assist or hinder or neither when caring for a child with Down syndrome	Nodes\\Experience of raising the child\Child level of dependence	3
Negative	What are the challenging aspects when caring for a child with Down syndrome. Eg poor behaviour	Nodes\\Experience of raising the child\Negative	96

Health	Health problems are notorious with children with Down syndrome. How has this impacted the experience of raising the child?	Nodes\\Experience of raising the child\\Negative\\Health	22
Work	Working and caring for a child with Down syndrome... is it possible? Does work suffer or is it part of daily life?	Nodes\\Experience of raising the child\\Negative\\Work	7
Positive	What are the good aspects when raising a child with down syndrome? What aspects are considered benefits?	Nodes\\Experience of raising the child\\Positive	117

Reports\\Experiencing of raising a child with DS

Page 1 of 2
2013/10/17 03:47 PM

Name	Description	Hierarchical Name	Number Of Coding References
Feelings of love	The feelings that caregivers have toward the child. Includes the caregivers' accounts of love felt toward the child of others within their environment eg: other children, community, the child's love towards others	Nodes\\Experience of raising the child\\Positive\\Feelings of love	4
Level of support	Support that the caregiver receives - the impact it plays in their lives	Nodes\\Experience of raising the child\\Positive\\Level of support	51
Support structures	What are the structures that the caregivers considers to be support?	Nodes\\Experience of raising the child\\Positive\\Level of support\\Support structures	47
Down syndrome KZN	The degree to which the association has been involved. Caregivers' level of dependence versus independence when considering DS KZN. Caregivers' perception of importance of DS KZN	Nodes\\Experience of raising the child\\Positive\\Level of support\\Support structures\\Down syndrome KZN	14
Protective feelings	Caregivers' need to shelter and protect the child from others. Including community, family etc.	Nodes\\Experience of raising the child\\Protective feelings	8
School	Whether it is desired versus undesired, the experiences of the child/ren at the schools (positive versus negative)	Nodes\\Experience of raising the child\\School	28
How others respond to you and child	Positive, negative, inquisitive, levels of prejudice and ignorance versus, warmth and understanding. What are people like when they see the caregiver and child?	Nodes\\How others respond to you and child	78
Community specifically	Within a cultural context - the community being those that are the neighbours, part of the church, seen regularly in the area/ malls and the like. Specific information from specific groups of people	Nodes\\How others respond to you and child\\Community specifically	11
Initial Reaction	What was the first feelings/ emotions experienced when finding out that the child has been diagnosed with Down syndrome?	Nodes\\Initial Reaction	121

Acceptance at this stage	Does the caregiver accept the child? Was this instantaneous? Did it occur later on?	Nodes\\Initial Reaction\Acceptance at this stage	20
Feelings of guilt or shame	Levels of self blame and guilt - blaming themselves for the child's diagnosis. Versus no feelings of shame and having better insight	Nodes\\Initial Reaction\Feelings of guilt or shame	13
Knowledge vs ignorance	What information was known about DS? What had to be learned? How did you find out? What is the level of knowledge now?	Nodes\\Initial Reaction\Knowledge vs ignorance	60

Appendix 15

Translator's CV

**CURRICULUM VITAE
Of
Mongezi Christopher Bolobo
G996/22 Msebe Road
P.O. KwaMashu
4360**

E-mail: bolofology@webmail.co.za

Home No: 031 503 7799

Cell no: 078 531 3582/ 071 8821 193

1. Personal Details

First Name(s) : Mongezi Christopher
Surname : Bolobo
Identity Number : 840930 5351 08 7
Gender : Male
Marital Status : Engaged
Home Language : isiZulu and SeSotho
Other Language Spoken : isiXhosa, English, Afrikaans and French (fair)
Residential address : G996 Msebe Road
P.O.KwaMashu
4360
Number of Dependants : Three (Mother, fiancée, and a son)
Drivers' License : In the process of acquiring one

2. Interest And Hobbies

South African Choral music.
Reading on Philosophy, religion and culture
Language discourse and Linguistics theory
Watching Soccer
Church Choir

3. Skills

Communication Skills
Public speaking Skills
Organizational Skills
Multilingual [5 South African Languages + French (fair)]

4. Formal Qualifications

4.1 Secondary School Education

High School Attended : Sivananda Technical High School
Highest Standard Passed : Matric (Grade 12)
Subject Passed : IsiZulu
English
Afrikaans
Biology
Physical Science
Motor Mechanics

4.2 Tertiary Education

Institution : University Of KwaZulu Natal
Course : BSocSci Honours :IsiZulu
Duration : 1 years
Year Completed : 2008
Achievement :Merit Certificate: Translation and Interpreting
Merit Certificate: Introduction to Lexicography

Institution : University Of KwaZulu Natal
Course : BSocSci: Media and Communication/ isiZulu
Duration : 3 years
Year Completed : 2007
Achievement : Merit Certificate: Advanced isiZulu A

5. Work Experience

5.1. Language Practice Experience.

I have worked in different translation projects with the following institutions/persons:

1. SANTED- terminology development
Prof. Nobuhle Hlongwa- 031 260 2510/2772
2. CNRS-France. Dr. Michel Lafon- translation of an isiZulu Novel to French
[michel.maikoro@gmail.co.za/](mailto:michel.maikoro@gmail.co.za) lafon@vjf.cnrs.fr
3. New Readers Publishers- Translation and Editing of Books for Publication
Sonya Keysner- 083 632 5424
4. SOAS-England.- Transcription and Translation of Research Interviews
Dr. Angela Impey – ai6@soas.ac.uk
5. PANSALB – transcription and translation

- Prof. Sihawu Ngubane – 031- 260 2055
6. Junior Lecturer in Translation and Intercultural Communication: UKZN
Prof. Ileana Dimitrui – 031 260 2334.
 7. PSP Study
 8. Asenze study
 9. BREC. UKZN

Current Employment

Name of Company : Glenmore Primary School
 Position : Educator
 Term of Office : January 2009- up to date
 Contact Person : Mr. D Spiterri (Principal of the school)
 Contact numbers : (031) 261 2164 / 082 9502 886

Previously

Name of Company : School of IsiZulu Studies (University of KwaZulu Natal)
 Position : Tutor
 Term of Office : January 2007- November 2008
 Reason for living : Contract ended.
 Contact Person : Prof. N.N. Mathonsi (Head of School)
 Contact Numbers : (031) 260 2510

Name of Company : School of English Studies (UKZN)
 Position : Tutor (Translation and Intercultural Studies)
 Term of Office : June 2008- November 2008
 Reason for living : Contract ended.
 Contact Person : Prof. I Dimitriu (Head of School)
 Contact Numbers : (031) 260 2334

6. References

1. Name : Prof. Nobuhle Ndimande-Hlongwa
 Occupation : Senior Lecturer in UKZN
 Contact No. : 031 260 2772
 082 8787 440
2. Name : Mr. Monde Nembula
 Occupation : Environmental Consultant
 Contact No : 083 9922 391
3. Name : Prof. N.N. Mathonsi
 Occupation : Head of School of IsiZulu Studies: UKZN.
 Contact Numbers : 031 260 2510



UNIVERSITY OF KWAZULU-NATAL

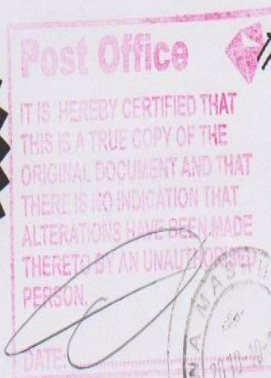
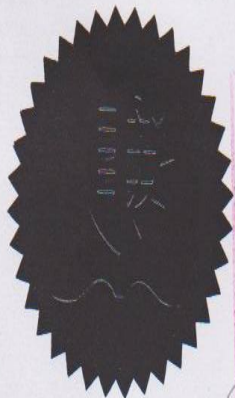
This is to certify that

Mongezi Christopher Bolofo

was admitted this day
at a congregation of the University
to the degree of

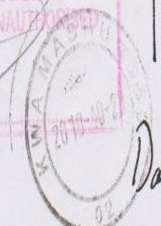
**Bachelor of Social Science Honours
(Zulu)**

having satisfied the conditions prescribed for the degree.



M W Makgoba
Vice-Chancellor

J J Meyerowitz
Registrar



D P McCracken
Dean

16 April 2009



UNIVERSITY OF KWAZULU-NATAL

This

MERIT CERTIFICATE

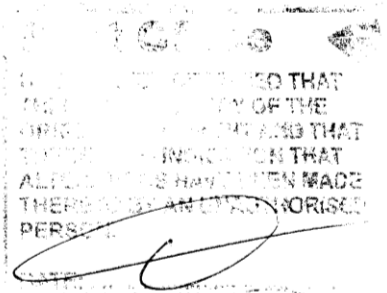
is awarded to

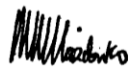
Mongezi Christopher Bolofo


for outstanding performance during 2008

in the module(s) listed below:

Translation and Interpreting




NM Mazibuko
Deputy Vice-Chancellor
and Head of College:
Humanities


D P McCracken
Dean: Humanities, Development
and Social Sciences

Appendix 16

Letter of Informed Consent (English) Participants

I, _____ (Full names), hereby give my consent
participate in the study entitled:

**THE EXPERIENCE OF RAISING A CHILD WITH DOWN SYNDROME:
PERCEPTIONS OF CAREGIVERS IN KWAZULU-NATAL**

Which will be conducted as part of the University of KwaZulu-Natal Westville Masters degree.

I consent to the sharing of my personal information, subjective feelings and opinions in this focus group for the purpose of this study.

I hereby acknowledge that I have been informed that this information that I share will be kept confidential and will only be used for the purposes of this study. I am aware that what I say will be recorded using a digital recorder only for the purposes of the study and I agree to this. I also acknowledge that I have been informed that I may withdraw from this study at any point should I choose to do so without and repercussions. I understand that there is no known or anticipated harm/ risk to me by engaging in this study.

I am aware that the researcher will offer debriefing should I need this to help me to deal with any emotional distress. I am aware that should I feel distressed I am able to take a break from the focus group, chose to stop speaking until I feel comfortable again or withdraw from the study. I understand that the researcher will also refer me to a counselor should I need it.

I acknowledge that all transport costs will be paid for by the researcher and I will not have to pay any money at all for engaging in this study. I understand that I will receive a copy of the consent form.

I completely understand what is written above and agree.

Signed: _____

At the place of: _____ on this date: _____

I hereby request a copy of the results of this study (please circle the appropriate response below):

Yes

No

If yes, please select your method of receiving your copy (please circle the appropriate response below):

Email Post Other (Please specify below)

Contact Details:

Researcher: M. Barr 084 840 4001 megz13@hotmail.com

Supervisor P.Naidoo 031 260 8258 naidoopg@ukzn.ac.za

Qualifications: (BOT (UDW), MOT (UKZN), CAMAG (ABIME))

Supervisor G. Rencken 031 260 7052 rencken@ukzn.ac.za

Qualifications: BOT (UP), MOT (UFS)

Research Office:

Postgraduate Officer: Phindile Nene 031 2608280 nenep1@ukzn.ac.za

Appendix 17

Letter of Informed Consent (isiZulu) Participants

Mina, _____ (Amagama agcwele), nginika
igunya lokuba ngibandakanywe ocwaningweni:

**OBHEKANA NAKHO EKUKHULISENI UMNTWANA ONE-DOWN SYNDROME:
IMIBONO YABANAKEKELI KWAZULU -NATALI**

Ezokwenziwa njengengxenywe yokuzuzisa iziqu zeMastazi eNyuvesi yaKwaZulu Natali

Nginika imvume yokuba ngabelane nolwazi lwami, imzwa yami ngokukhulunywa ngakho kanye nemibono yami kuleli qembu elididiyelelwe ucwaningo ngezinhloso zalolu cwaningo.

Ngiyazi futhi ukuthi engikushoyo kuyoqoshwa kusetshenziswa isiqophi ngenhloso yalolu cwaningo futhi lokhu ngiyagunyaza. Ngiyazisa futhi ukuthi ngazisiwe ukuba ngingahoxa kulolu cwaningo noma kunini lapho ngikhethe ukwenza njalo ngale kwemibandela, futhi ngiyokwenza njalo uma kunesidingo.

Ngiyaqonda ukuthi akukho bungozi obazekayo nobulindelekile kimina ngokuba yiongxenywe yocwaningo. Ngiyazi ukuthi umcwaningi uyonikezela ngengxoxo uma ngiyidinga ukuze ngisizakale ekubhakaneni nengcindezi yemizwa. Ngiyazi futhi ukuthi uma ngizizwa nginesinxo ngingakwazi ukuthatha ikhefu eqenjini, ngikhethe ukungabe ngisakhuluma kuze kube sengikulungele noma ngihoxe ocwaningweni. Ngiyaqonda ukuthi umcwaningi uyongidlulisela kumeluleki uma ngikudinga lokho.

Ngiyamukela ukuba zonke izindleko zokugibela ziyothwalwa ngumcwaningi futhi angiyukukhokha mali ngokuba yingxenywe yalolu cwaningo. Ngiyaqonda ukuthi ngizothola ikhophi yaleli fomu lemvume.

Ngiyakuqondisisa konke okubhalwe ngenhla futhi ngiyakuvuma

Isayinwe : _____

Endaweni yase: _____ ngalolu suku: _____

Ngiyacela ukuthola ikhopho yemiphumela yalolu cwaningo (sicela ukuba ukokelezele impendulo efanele ngezansi):

Yebo

Cha

Uma impendulo kunguyebo, sicela ukhetha indlela othanda ukuyithola ngayo leyo khophi
(sicela ukuba ukokelezele impendulo efanele ngezansi):

i-Email

Iposi

Okunye (Sicela ucacise ngezansi)

Imininingwane yokuxhumana :

Umcwaningi: M. Barr 084 840 4001 megz13@hotmail.com

Umeluleki : P.Naidoo 031 260 8258 naidoopg@ukzn.ac.za

Iziqu: (BOT (UDW), MOT (UKZN), CAMAG (ABIME)

Umeluleki : G. Rencken 031 260 7052 rencken@ukzn.ac.za

Iziqu: BOT (UP), MOT (UFS)

Ihhovisi Lezocwaningo:

Postgraduate Officer: Phindile Nene 031 2608280 nenep1@ukzn.ac.za

Appendix 18

Gatekeeper Permission

Down Syndrome Association KZN

P O Box 28307, Malvern, Durban. 4055
Telephone: 031-464-2055 Fax: 031-9036930

Email: downskzn@iafrica.com
Website: www.downsyndrome.org.za
Non Profit Organization - 002-489 NPO & PBO 930002626



Ms Megan Barr
E mail : megz13@hotmail.com


Dear Megan

Further to your e mail dated 6th February 2013 the Down Syndrome Association KZN confirm that you may have access to our database for your studies. We mention that this will be under supervision from our office.

We also mention that any of our families participating must be allowed to do so of their own free will.

Looking forward to assisting you as much as possible

Kind regards


Caroline Willis
Branch Coordinator

Appendix 19
Confidentiality agreement

Researcher

I, _____ (Full name), agree not to disclose any information and data received during the data gathering process in both the focus groups and the possible interviews. I hereby acknowledge that the information given by the participants within the data gathering context is confidential and may thus not be shared with anyone who is not directly involved in the research study.

I also agree to the accurate transcription of all data collected in the focus group sessions and possible interviews. I agree that I will not present with bias or prejudice in any form during the data collection or analysis process. I agree to upholding all ethical considerations, highlighted in the research proposal, in my handling of the participants and the data of the research study.

I completely understand and agree to what is written above.

Signed: _____

At the place of: _____ on this date: _____

Appendix 20

Confidentiality agreement

Interpreter/ Co-facilitator

I, _____(Full names), agree to not disclose any information gathered during this data gathering process with any individual who is not directly involved in this study. I agree provide the most accurate translation of all information provided by the participants within the study, to the best of my ability. I agree in no way to alter the opinions expressed by the participants whilst translating. I once again agree to translate the information as accurately as my ability and knowledge base allows.

I completely understand and agree with what is written above.

Signed: _____

At the place of: _____ on this date: _____

Appendix 21

Getting to know the participants (focus groups & interviews)

Focus group 1

Name	Background
Thembi	A 43 year old African, isiZulu speaking female who cares for a 5 year old male with Trisomy 21. The child is her biological son. Thembi has a supportive, loving husband and family and speaks highly of them. She also reported that her community, for the most part, have been accepting and warm towards her and Tokozo, her child. She noted that the father's acceptance has influenced the perceptions of others.
Silindile	A 36 year old African, isiZulu speaking female who cares for a 5 year old female with Trisomy 21. The child is her biological daughter. Silindile reported that she initially had a negative reaction to the child's diagnosis but her family and community have assisted her and supported her. She noted that through support groups she has met other caregivers and managed to accept Fanele, her child and love her.
Thando	A 48 year old African, isiZulu speaking female who cares for a 6 year old female with Trisomy 21. The child is her biological daughter. Thando reported that she has only recently begun to play an active role in her daughter, Ayanda's life. Previously, she was extremely ill and her eldest daughter took the role of caregiver for her younger daughter with Down syndrome. Her older daughter passed away this year and she is dealing with her grief and assuming a new role.
Fikile	A 41 year old African, isiZulu speaking female who cares for an 8 year old male with Trisomy 21. The child is her biological son. Fikile reported that her husband did not accept the child to be his own due to no 'disabilities' within his family. As a result he and his family have chosen to have nothing to do with Sabelo, the child. Fikile reported that she loves her child dearly and does not need a man to help her raise her child.
Fanele	A 42 year old African, isiZulu speaking female who cares for a 6 year old female with Trisomy 21. The child is her biological daughter. Fanele experienced difficulties with her community and even some family

	members. She reported that people are ignorant and do not want to touch or care for Anele, her child. She even reported a situation of abuse by her sister when ‘punishing’ her child involving burning her hands.
Bongi	A 43 year old African, isiZulu speaking female who cares for a 5 year old male with Trisomy 21. The child is her biological son. Bongi has had a mixture of reactions from her family and community. She has a husband who left her initially and returned when he lost his employment. Bongi feels that he has come back to benefit from her child’s grant. Bongi reports that her neighbours are extremely loving towards her and Simiso, her child.
Thandi	A 28 year old African, isiZulu speaking female who cares for a 6 year old female with Trisomy 21. The child is her biological daughter. Thandi was shocked and sad when she had Mbali, her child. She reported that she felt that her ancestors were punishing her for having a child without being married. She was confused as she was young and below the age of 35. She reported that her mother had passed away around the time of the birth and maybe that was the reason.
Nonko	A 42 year old African, isiZulu speaking female who cares for a 7 year old female with Trisomy 21. The child is her biological daughter. Nonko accepted her child from birth. Although she was surprised to have Lebo, she reported that if it is God’s will for her to have such a child then she is happy to be the child’s mother. She has a good support system of family and community members and reports that she has met a lot of people and gained extensive knowledge through having a child with Down syndrome.

Focus group two

Name	Background
Busi	A 56 year old African isiZulu/English speaking female caring for an 11 year old female with Trisomy 21. The child is her biological daughter. Busi reported that when her daughter, Sandile was born her husband disowned her and the child. He refused to accept the child as being his and chose to leave. She noted that although she has had difficulties with her family and community, her Church has been a constant means of support, love and acceptance for her and Sandile. She feels that it is ‘God’s plan’.

Precious	A 38 year old African, isiZulu/English speaking female who cares for a 7 year old female with Trisomy 21. She is the child's biological mother. She reported that when her daughter Dudu was born, her husband and his family shunned her. She reported that he implied that she had been unfaithful as the child could not possibly be his. She noted many tough times with a lack of acceptance by her family and community however she is adamant that one has to be strong for their child.
Lungi	A 35 year old African, isiZulu/English speaking female who cares for a 5 year old male with Trisomy 21. Lungi is the biological parent and lives with her older son and daughter, her husband and her youngest son, Sthembiso who has Down syndrome. She reported that her husband is loving and accepting of the child and although his family were resistant initially, he stood up for her and the child. Her husband's family are now loving and supportive.
Nozipho	A 37 year old African, isiZulu/English speaking female who cares for a 6 year old female with Trisomy 21. Nozipho is the biological mother of the child. She reported that she has had difficulty mostly with her husband who does not take an active role in her daughter, Sne's life. Although they live together, he does not help to support them and does not attend any support groups or clinic visits with her. She suspects that he is more interested in Sne's care dependency grant rather than caring for them. She showed bitter and resentful emotions within the interview.

Individual Interview:

Name	Background
Brenda	A 40 year old, coloured female who cares for a 6 year old daughter with Trisomy 21. Brenda lives in a suburban area with her husband, two older sons and Haley, her daughter with Down syndrome. She reported that initially she was relieved when she found out about Haley's diagnosis as the doctor's reaction (facial expression) on delivery was so negative she was convinced she had lost her baby. Brenda is a strong, determined woman who made it her mission to learn all there is to know about Down syndrome. She has convinced the principal at a mainstream school to allow Haley to attend

	with the help of a facilitator. Since then, two other children with Down syndrome have also been accepted. Brenda sees herself as an advocate for Down syndrome and is helping to educate her community.
--	--

Dyad Interview:

Name	Background
Craig and Sandra	Craig is a white, 52 year old male and Sandra is a white, 48 year old female. They are happily married and care for their 11 year old daughter named Crystal. Crystal has been diagnosed with Trisomy 21. They live in a suburban area in a 3 bedroom home with a garden and pool. They reported that they moved in the last year from a flat which was difficult due to Crystal and her older sister Nancy having to share a room. They reported to have an extremely strong support system of community members, friends and family. They noted that they are privileged to have each other to lean on in challenging times and feel that raising a child with Down syndrome as a single parent would be unfathomable for them.

Triad Interview:

Name	Background
Jenny	Is a white 42 year old female who cares for her 9 year old son with Trisomy 21. She is the mother of two older daughters and her youngest, James has Down syndrome. She lives in a suburban area with her three children and domestic worker. She reported that her marriage fell apart after James was born and is supported primarily by her older daughters, domestic worker, Fran and her sister. She open says that she would not change James for the world even though she often feels as if she has 'hit burn-out'.
Kerry	Is an 11 year old, white female who is Jenny's eldest daughter. She helps her mom, younger sister and Fran care for James and fondly reported that James listens to her compared to the other women in his life. She stated that her friends have accepted him and often let him join in when they play.
Fran	Is a 29 year old, African female who assists in caring for James, her employer's son. She began working for Jenny and was unaware about

	<p>James' diagnosis. She reported that she learned from James and now knows what he likes and dislikes. She also stated that she is able to understand him as he has deaf speech due to multiple ear operations. She likes to think of herself as his other mother and enjoys living with Jenny and her family.</p>
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Appendix 22

Proposed request for Permission from Hospital CEOs

THE EXPERIENCE OF RAISING A CHILD WITH DOWN SYNDROME: PERCEPTIONS OF CAREGIVERS IN KWAZULU-NATAL

Attention: CEO/Hospital Manager/Medical Manager

My name is Megan Barr (208506169) and I am currently engaging in my Master's study in Occupational Therapy through the University of Kwazulu-Natal Westville. Through my research and subsequent literature review it has become apparent that there is limited research on Down syndrome in the South African context let alone within Kwazulu-Natal. For the purpose of my study, caregivers do not only denote to parents but can be grandparents, siblings neighbours or anyone who predominantly looks after the child.

Through the conduction of my study I aim to obtain data in terms of the psychosocial and interpersonal dynamics that surround raising a child with Down syndrome. I endeavor to produce comprehensive results in order to allow for health professionals, caregivers and the public to gain an understanding into the lives of these caregivers. Through understanding health care professionals as well as society will be able to adopt an empathetic standing to ensure that both therapy and support in general are more holistic.

I am asking for permission to conduct my study utilizing members from the hospital that attend the Down syndrome clinics. My study is twofold and entails a survey with an array of questions to be completed by approximately 50 people as well as two focus groups that will be held after the data from the survey has been collected. Due to the dynamics of KwaZulu-Natal I aim to utilize individuals from the hospital as well as members of The Down syndrome Association KwaZulu-Natal to allow for diversity to be achieved. The survey will be available in isiZulu and English and only requires that the possible participant ticks the appropriate option. The focus group will entail two discussion groups of approximately 6-8 participants in each.

All aspects will be organized by the researcher including all costs and arrangement of times. The researcher plans to see the participants during the allotted clinic times so as not to interfere with treatment. The only considerations for the hospital are allowing the

research to occur and the possible use of a nurse/interpreter to assist any participants that are having difficulty with the survey.

Confidentiality of the research and findings will be maintained to the researcher's best ability and anonymity will be maintained for both the survey and the focus groups. Participants will receive coded identities for the purpose of the focus groups and their true identities will only be known by researcher. Participants will be made aware of the purpose of the study and it will be highlighted that participation is entirely voluntary. It is also important to note that through the conduction of my study there will be no known or anticipated risk to any of the participants involved.

Research findings will be made available to you in report form should you find this of interest.

The results will be published at a later time within an acclaimed journal as well as possible presentations both on a national and international level.

Please feel free to contact the researcher or official supervisors should you have any queries with regards to the study.

Thanking you in anticipation,

Megan Barr

Occupational therapist

Contact Details:

Researcher: M. Barr 084 840 4001 megz13@hotmail.com

Supervisor P.Naidoo 031 260 8258 naidoopg@ukzn.ac.za

Qualifications: (BOT (UDW), MOT (UKZN), CAMAG (ABIME)

Supervisor G. Rencken 031 260 7052 rencken@ukzn.ac.za

Qualifications: BOT (UP), MOT (UFS)

Research Office:

Postgraduate Officer: Phindile Nene 031 2608280 nenep1@ukzn.ac.za

Appendix 23

Proposed request for Permission from Hospital CEOs (2)

CEO/Hospital Manager/Medical Manager

THE EXPERIENCE OF RAISING A CHILD WITH DOWN SYNDROME: PERCEPTIONS OF CAREGIVERS IN KWAZULU-NATAL

I understand the purpose and details of the above mentioned Master's study. All aspects have been explained to me by the researcher and I understand the involvement of the hospital and Down syndrome clinics within the study. I hereby grant the researcher permission in order to conduct the study at this establishment.

Name of CEO/Hospital Manager/Medical Manager

Signature

Date

Contact Details:

Researcher: M. Barr 084 840 4001 megz13@hotmail.com

Supervisor P.Naidoo 031 260 8258 naidoopg@ukzn.ac.za

Qualifications: (BOT (UDW), MOT (UKZN), CAMAG (ABIME)

Supervisor G. Rencken 031 260 7052 rencken@ukzn.ac.za

Qualifications: BOT (UP), MOT (UFS)

Research Office:

Postgraduate Officer: Phindile Nene 031 2608280 nenep1@ukzn.ac.za

Appendix 24

Copy of the proposed Questions to be given to the participants (English)

1. “What was your immediate reaction when discovering that the child has Down syndrome? “
2. How would you describe your experiences of raising a child with Down syndrome?
3. Do you think this has had an effect on the rest of your family and if so how/what?
4. Describe how other people respond to you and the child.
5. What advice could you give to other caregivers in the same or similar situation?

Note: The above questions are to be a guide for you to gain a sense of what type of questions will be asked by the researcher. The questions might change slightly due to the discussion aspect of the focus group

Contact Details:

Researcher: M. Barr 084 840 4001 megz13@hotmail.com

Supervisor P.Naidoo 031 260 8258 naidoopg@ukzn.ac.za

Qualifications: (BOT (UDW), MOT (UKZN), CAMAG (ABIME)

Supervisor G. Rencken 031 260 7052 rencken@ukzn.ac.za

Qualifications: BOT (UP), MOT (UFS)

Research Office:

Postgraduate Officer: Phindile Nene 031 2608280 nenep1@ukzn.ac.za

Appendix 25

Copy of the proposed Questions to be given to the participants (isiZulu)

Imibuzo ehlongozwayo yeqoqo elididiyelelwe ukucwaninga:

1. “Yini eyokuqala eyakufikela ngesikhathi uthola ukuthi umntwana une-Downs syndrome?”
2. Ungasichaza kanjani isikhathi sakho ukhulisa umntwana one-Downs syndrome?
3. Ucabanga ukuthi lokhu kube nomthelela kuwo wonke umndeni wakho futhi uma kunjalo kube nomthelela onjani/muni?
4. Ake uchaze indlela abantu abanithatha ngayo wena nomntwana.
5. Ungabeluleka uthini abanye abanakekeli abasesimweni esifana nesakho?

Qaphela: Imibuzo engenhla izokuba yisibonakaliso ukuze uthole ukuthi umcwaningi uzobuza hlobo luni lwemibuzo. Imibuzo ingashintsha kancane ngenxa yokuthi iqembu lizobe lixoxa

Imininingwane yokuxhumana :

Umcwaningi: M. Barr 084 840 4001 megz13@hotmail.com

Umeluleki : P.Naidoo 031 260 8258 naidoopg@ukzn.ac.za

Iziqu: (BOT (UDW), MOT (UKZN), CAMAG (ABIME))

Umeluleki : G. Rencken 031 260 7052 rencken@ukzn.ac.za

Iziqu: BOT (UP), MOT (UFS)

Research Office:

Postgraduate Officer: Phindile Nene 031 2608280 nenep1@ukzn.ac.za

Appendix 26

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THE EXPERIENCE OF RAISING A CHILD WITH BY MEGAN BARR

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CHAPTER ONE INTRODUCTION

1.1 Introduction

This chapter presents a brief history and progression of Down syndrome in terms of development and understanding of the condition. It explores decreased knowledge with regards to the syndrome within the South African and more specifically the KwaZulu-Natal context. Furthermore it allows for the participants' experiences to be explored in order to increase awareness of the difficulties and the benefits of raising a child with Down syndrome as well as the barriers and limitations experienced.

For the purpose of this study, the title of caregiver denotes those individuals who predominantly care for the child with Down syndrome, which may result in the role being shared e.g. between a mother and a grandmother. By utilizing participants that predominantly care for the children rather than just parents, it allows for a more accurate representation of the lives of these individuals within the KwaZulu-Natal Province.

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2013 Dissertation 2013 Dissertation - DUE 31-Dec-2013

Originality GradeMark PeerMark

THE EXPERIENCE OF RAISING A CHILD WITH BY MEGAN BARR

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104 CHAPTER ONE INTRODUCTION

1.1 Introduction

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PAGE: 1 OF 169 26 November 2013 Tuesday