

**EXPLORING PERSPECTIVES OF
SOUTH AFRICAN FATHERS
OF A CHILD WITH
DOWN SYNDROME**

**By
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TABLE OF CONTENT

DEDICATION	i
ACKNOWLEDGEMENTS	ii
DECLARATIONS	iii
ABSTRACT	iv
WELCOME TO HOLLAND	vi

CHAPTER ONE

ORIENTATION, PROBLEM STATEMENT, RESEARCH AIM, CLARIFICATION OF CONCEPTS, RESEARCH DESIGN, RESEARCH PROCEDURES AND STUDY OUTLINE

1.1.	INTRODUCTION	1
1.2.	BACKGROUND AND CONTEXTUALIZATION	3
1.3.	PURPOSE OF THE STUDY	9
1.4.	FORMULATION OF RESEARCH PROBLEM	9
1.4.1.	Primary Research Question	10
1.4.2.	Secondary Research Questions	10
1.5.	RESEARCH OBJECTIVES	11
1.5.1.	Primary Objective	11
1.5.2.	Secondary Objectives	11
1.6.	DEMARCATION OF THE STUDY	11
1.7.	CLARIFICATION OF CONCEPTS	12
	• Down syndrome	12
	• Typically developing	13
	• Differently abled	13
	• Intellectual disability	14

• Fatherhood	15
• Fathering	15
• Parenting	16
• Ontological	16
• Epistemological	17
• Phenomenology	17
1.8. RESEARCH DESIGN	18
1.8.1. Philosophical Paradigm	18
1.8.2. Theoretical Framework	21
1.8.3. Research Approach	25
1.8.4. Research Methodology	29
• Literature review	29
• Sampling	31
• Privacy and confidentiality	31
• Data generation	33
• Data analysis	34
• Distinctiveness of the qualitative report	36
1.9. ETHICAL MEASURES	37
1.10. RESEARCH OUTLINE	39
1.11. CONCLUSION	40

CHAPTER TWO

LITERATURE REVIEW ON ASPECTS OF FATHERHOOD

2.1. INTRODUCTION	41
2.2. DEFINITION OF FATHERHOOD	41
2.3. BECOMING A FATHER	42

2.4.	HISTORIC AND CONTEMPORARY FATHERHOOD PERSPECTIVES	45
•	Historical perspectives	45
•	Contemporary perspectives	47
2.5.	FATHERHOOD: CHILDREN WITH DISABILITIES AND DELAYS	50
2.6.	THEORETICAL PERSPECTIVES RELATED TO FATHERHOOD	51
2.6.1.	The Father according to Freud	52
•	The Oedipus complex	52
•	Main premises of Freud's theory	54
•	Structure of personality	54
•	Freud's inference	57
2.6.2.	The Father according to Parsons	57
2.6.3.	Bandura's Social-Learning Theory	59
2.6.4.	Attachment Theory	60
2.6.5.	Family Systems Theory	61
2.6.6.	Social Identity Theory	62
2.7.	ATTACHMENT	63
•	Benefits of attachment for the child	63
•	Benefits of attachment for the father	63
2.8.	THE ROLES OF THE CONTEMPORARY FATHER	64
•	Participator / problem solver	65
•	Playmate	65
•	Principled guide	66
•	Provider	67
•	Preparer	69
2.9.	CHILD-REARING APPROACH OF THE FATHER	70
2.10.	WHO IS THE IDEAL FATHER?	72

2.11.	RESPONSIBLE FATHERHOOD	74
	• Involvement	75
	• Consistency	77
	• Awareness	78
	• Nurturance	78
2.12.	CONCLUSION	79

CHAPTER THREE

DOWN SYNDROME: A LITERATURE OVERVIEW

ON ETIOLOGICAL BACKGROUND

AND ASPECTS RELATING TO THE FATHERING EXPERIENCE

3.1.	INTRODUCTION	80
3.2.	WHAT IS DOWN SYNDROME?	81
	• Primary features of Down syndrome	83
	• Factors associated with the development of children with DS	84
3.3.	DOWN SYNDROME: BACKGROUND ON THE FATHERING EXPERIENCE	85
3.4.	RESEARCH ON FATHERS OF CHILDREN WITH DOWN SYNDROME	87
3.4.1.	Historical Perspectives	87
3.4.2.	Contemporary Perspectives	92
3.4.3.	The Down syndrome Advantage	97
3.5.	IMPACT OF THE CHILD WITH DOWN SYNDROME ON THE FATHER	98
3.6.	DEALING WITH THE GRIEF	100
3.7.	ADJUSTMENT AND ADAPTATION	102
3.8.	FATHER'S RESILIENCE AND COPING	105
3.9.	SOURCES OF SUPPORT FOR THE FATHER	106
	• Social networks - church and community	107
	• Parent support networks	107

• A proposed chapter for fathers	108
• Information	109
• Friends and family	109
• Fathers' experience with the medical fraternity	111
3.10. AFRICAN PERSPECTIVES OF DOWN SYNDROME	112
3.11. CONCLUSION	117

CHAPTER FOUR

RESEARCH DESIGN AND METHODOLOGY

4.1. INTRODUCTION	118
4.2. STATEMENT OF RESEARCH PROBLEM	118
4.3. AIMS AND OBJECTIVES OF THIS STUDY	118
4.4. RESEARCH APPROACH	119
• Qualitative approach	119
• Objectives of the qualitative approach	119
• Characteristics of the qualitative approach	121
4.5. RESEARCH PARADIGM	124
• Constructionism	126
• Interpretivism	126
• Phenomenological paradigm	127
4.6. ROLE OF THE RESEARCHER	128
4.7. RESEARCH DESIGN	131
4.7.1. Research Methodology	134
• Literature review	134
• Sampling	136
• Qualitative data generation	140
• Research instruments and procedure	143

• The researcher as instrument of data generation	146
4.8. DATA ANALYSIS	147
• Thematic analysis	148
4.9. MEASURES OF TRUSTWORTHINESS	153
• Bracketing	153
• Validity, reliability, dependability, credibility, transferability, confirmability	154
4.10. CONCLUSION	158

CHAPTER FIVE

ANALYSIS, INTERPRETATION AND DISCUSSION OF FINDINGS

5.1. INTRODUCTION	160
5.2. GENERAL OVERVIEW OF RESULTS	164
5.2.1. THEME ONE: INTRA-PERSONAL EXPERIENCE OF THIS LIFE EVENT	164
5.2.1.1 Intra-personal dynamics related to the diagnosis	165
• Emotional subsystem	166
• Physical subsystem	170
• Cognitive subsystem	171
• Behavioural subsystem	171
• Spiritual subsystem	174
5.2.1.2 Life span dynamics of intra-personal functioning	175
• Emotional subsystem	176
• Physical subsystem	179
• Cognitive subsystem	182
• Behavioural subsystem	185
• Spiritual subsystem	188
5.2.2. THEME TWO: INTER-PERSONAL EXPERIENCES OF THE FATHER	189
5.2.2.1 Relationship to self	189

5.2.2.2	Spousal relationship	191
5.2.2.3	Father's relationship to siblings of the child with Down syndrome	194
5.2.2.4	Father's relationship to friends	196
5.2.2.5	Father's relationship to family	200
5.2.3.	THEME THREE: COLLECTIVE EXPERIENCE OF DOWN SYNDROME	200
5.2.3.1	Experiences of support	201
5.2.3.2	Community reaction	207
5.2.4.	THEME FOUR: MANAGING THE LIFE EVENT	208
5.2.4.1	Parenting experience of his child with Down syndrome	208
5.2.4.2	Role as father of a child with Down syndrome	210
5.2.4.3	Moving forward: supporting other fathers	211
5.3.	CONCLUSION	212

CHAPTER SIX

IMPLICATIONS, RECOMMENDATIONS AND CONCLUSIONS

6.1.	INTRODUCTION	214
6.2.	DELIMITATIONS OF THE STUDY	214
6.3.	MAIN CONCLUSIONS	215
6.4.	GENERAL OVERVIEW ON IMPLICATIONS AND RECOMMENDATIONS	215
6.4.1.	THEME ONE: INTRA-PERSONAL EXPERIENCE OF THIS LIFE EVENT	216
6.4.2.	THEME TWO: INTERPERSONAL EXPERIENCES OF THE FATHER	226
	• Relationship to self	226
	• Spousal relationship	228
	• Father's relationship to siblings	229
	• Father's relationship to friends and family	231
6.4.3.	THEME THREE: COLLECTIVE EXPERIENCE OF DOWN SYNDROME	232
	• Educational institutions	233

• Support groups	234
6.4.4. THEME FOUR: MANAGING THE LIFE EVENT	235
• Parenting experience of his child with Down syndrome	236
• Supporting Other Fathers: Moving Forward	238
6.5. LIMITATIONS OF THIS RESEARCH STUDY	242
6.6. SUGGESTIONS FOR FUTURE RESEARCH	244
6.7. FINAL CONCLUSION	246
REFERENCES	248
ADDENDUM A	293
ADDENDUM B	295
ADDENDUM C	298
ADDENDUM D	305
LIST OF FIGURES AND TABLES	325

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***YOU ARE THE MASTER OF YOUR FATE,
YOU ARE THE CAPTAIN OF YOUR SOUL.***

-William Ernest Henley-

I can promise that this road has more laughter than tears. There will be difficult days, but there will also be days when you look in his eyes, or see him playing with his sister, or lie next to him and hear him sleep, where you cannot believe how blessed you are. One day you'll look in his face and the DS features will be beautiful to you, because it is a part of him. This is not a tragedy... it's just different to what you expected... (Father)

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DECLARATIONS

I, Heidi Webber, hereby declare that the thesis entitled: EXPLORING PERSPECTIVES OF SOUTH AFRICAN FATHERS OF A CHILD WITH DOWN SYNDROME is my own work and has not previously been submitted for assessment to another University or for another qualification.

.....

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.....

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To whom it may concern

This letter should serve to verify that I did the language editing of Mrs. Heidi Webber's thesis.

In support of my ability to do so I would like to state that I have been an educator for approximately thirty years as well as a principal for part of my career.

.....

MR. M.C. LOTZ

.....

DATE

ABSTRACT

A mere glance at a family photograph of the Victorian era leaves little doubt of the position of the figure exuding impervious, authoritarian detachment. Austere, rigid and solemn, it is not hard to guess who cast the shadow over the picture. Arrestingly imposing in his role as backbone of the family, this is the nineteenth century legacy image of the father. However, the last century has seen fatherhood redefine itself and the more liberal, lenient and openly loving figure replaced the strict patriarchal model. In contemporary times, fathers are regularly seen comfortably behind a stroller, outdoors with children on their shoulders, at home tussling with their children, and considerably more involved in school and social events. Unashamedly, fathers have moved toward both acknowledging and displaying a softer paternal image. By definition fatherhood is a decidedly individual concept and a unique experience, involving much more than being the male parent in a family, the family protector, or the provider of paycheques.

Although the past decade has seen a surge of research and interest in fatherhood with an increased recognition that the involvement of fathers contribute to the well-being, cognitive growth and social competence of their children, there remains a deficit in research on the experiences, perceptions and involvement of fathers of children diagnosed with Down syndrome. And whilst most of this knowledge base is extrapolated from studies about the mother's experience, true understanding requires that fathers are studied directly. Mothers and fathers respond differently to the pressure associated with raising a child with Down syndrome and literature supports the common view that men are less likely and easy to engage in therapy than women, are less likely to attend therapy, or seek help for physical or psychological problems. For fathers of any differently abled child, the distance between the idealized fathering experience and the actual one may be enormous.

Based upon the patriarchy model of the family, in many conventional homes, the wife and mother is like a thermometer, sensing and reflecting the home's temperature, whilst the father and husband is like the home's thermostat, which determines and regulates the temperature. The equilibrium of the father plays an important role in his 'thermostat settings' to set the right temperature in the marriage and his family. Having a differently abled child is almost never expected and often necessitates a change in plans as the family members adjust their views of their own future, their future with their child, as well as how they will henceforth operate as a family.

Some fathers may experience uncertainty about their parenting role of a child diagnosed with Down syndrome, often resulting in peculiar behaviours of the father. This may include engrossing themselves into their work, hobbies, sport, and so forth, almost abdicating their duty as father; believing that the mother knows best (sometimes using their own lack of knowledge as a cop-out); or, they simply withdraw because the mother takes such complete control of every aspect of the child that the father feels inadequate, superfluous, and peripheral as parent.

Each parent grieves the 'loss' of the child they expected in their own individual way. However, such a highly emotive situation may be compounded by the following aspects: the undeniable pressure of caring for the differently abled child; the additional financial burden; a waning social life; and, the incapacity to cope emotionally whilst invariably displaying the contrary purely to create the illusion that they are indeed coping. Fathers need to develop strategies and skills to cope with the very real and practical needs of parenting their child with Down syndrome, to furthermore minimize relationship conflict and misunderstanding, and to support their child's optimal development. How these specific issues are embraced and managed may dramatically influence the peace and harmony of family life as well as the marital relationship.

This study explores the perspectives of fathers of a child with Down syndrome to ultimately support this unique journey as they navigate their way through "*Down*"town Holland, as illustrated in the analogy to follow.

WELCOME TO HOLLAND

(Emily Pearl Kingsley)

I am often asked to describe the experience of raising a child with a different ability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum, the Michelangelo David, the Gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later the plane lands. The stewardess comes in and says, "*Welcome to Holland.*"

"*Holland?!?*" you exclaim. "What do you mean *Holland??* I signed up for *Italy!* I'm *supposed* to be in Italy. All my life I've dreamed of going to Italy!" But there's been a change in the flight plan. They've landed in Holland, and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It's just a *different* place. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you never would have met.

It's just a DIFFERENT place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills... Holland has tulips... Holland even has Rembrandts. But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. For the rest of your life, you will say, "Yes. *That's where I was supposed to go. That's what I had planned.*"

And the pain of that will never, ever, ever go away because the loss of that dream is a very very significant loss. But if you spend your life mourning the fact that you *didn't* get to Italy, you may *never* be free to enjoy the very special, the very lovely things... about Holland.

CHAPTER ONE

ORIENTATION, PROBLEM STATEMENT, RESEARCH AIM, CLARIFICATION OF CONCEPTS, RESEARCH DESIGN, RESEARCH PROCEDURES AND STUDY OUTLINE

1.1. INTRODUCTION

Parenting is, without doubt, a tough job. Add an additional challenge like a diagnosis of any sort and that job becomes *much* tougher (Takataya, Yamazaki & Mizuno, 2016: 1). We live in a competitive culture where expectations are ever higher, with compassion seemingly lower in a society which is more fragmented and fluid (Baker & McNulty, 2011: 853). Furthermore, it seems as if modern society is hesitant to embrace disability and in many cases actively discriminates against it (Ovens, 2009: 2). This is unquestionably the reality of every individual and every family affected by a disability diagnosis (Dowling, Nicoll & Thomas, 2006: xiii), a situation that does not call for pity, but rather for understanding, compassion and empathy. Sometimes even from others in the same boat.

Cuskelly, Hauser-Cram and Van Riper (2008: 109) acknowledge the evident lack of research about direct interventions aimed at reducing stress or increasing well-being in parents of a child with Down syndrome (hereafter referred to as DS), with specific reference to the clear need for understanding how best to provide support for especially fathers. Takataya et al (2016: 1) and Skotko, Levine and Goldstein (2011: 2336) concur that there is much we do not know about the experiences of fathers in their parenting role of a child with DS. Apart from the researcher's previous study investigating the family dynamics of having a child and a sibling with DS (Webber, 2011), the only other documented South African based related research was conducted thirty three years ago by Lindenberg (1983). As with most studies involving DS, the latter compared stress of mothers and fathers of children with DS and a matched control group of parents of typically developing children in terms of the pre-school experience. Hence, the current study is significant as it extends research specifically to how South African fathers are experiencing their fathering role of a child with DS.

This research is driven by equal measures of the researcher's personal interest and intellectual curiosity (Fouché & De Vos, 2011: 84) regarding DS, advancing from her Master's research study to an explicit focus on South African fathers of a child with DS. Hence, centred on the notion of "informed inquisitiveness" (Monette, Sullivan & DeJong,

2008), the choice of topic reflects personal relevance of an ability to relate to contemporary family challenges in general and, more specific, challenges of families with a differently abled child. Fouché and Schurink (2011: 308) confirm that personal interest and curiosity is of particular importance to a qualitative research study. However, it needs to be clarified from the outset that, despite the researcher's undeniable interest in DS, this study, as an ethical empirical endeavour, transcends any personal journey. Accordingly, the topic was thoughtfully deliberated to ultimately contribute to the current limited disciplinary body of knowledge about the experiences and perspectives of South African fathers of a child with DS. Notwithstanding any connection of the researcher to the DS community, this study remains essentially for and about fathers, fatherhood and the fathering experience.

The past thirty years have seen a growing trend towards humanistic disability studies (Singh, 2012: 522). Thus, much of the literature in the field of DS studies is more than ten years old, especially related to fathers. Throughout this study the researcher refers to relevant writers in the field whose seminal work may not fall into the ten year date range. Using older references does not indicate an ossified view; rather it indicates that despite intensified effort, more recent literature simply could not be traced. The researcher looked for advice in three useful texts on research to justify using older references in this study. In describing how to undertake a literature search, Creswell (2007) did not mention a date range at all; while Merriam (2009) and Cohen, Manion & Morrison (2011) both suggested that only the most recent work in the area should be included in a literature review. With so many journals and publications today, it would be very difficult for anyone to read all the research on a subject. The researcher relied on common sense and took note of what other researchers in the field had done in this regard. Although every effort was made to use the latest references, older references that are often cited by other researchers, albeit older, was deemed worth including.

The sections to follow in this chapter provide the conceptual framework of this study. The term conceptual framework is not clearly defined. Used traditionally in methodology textbooks, it loosely refers to the *organising image* of the phenomena to be investigated, including which questions are to be answered by the research and how empirical procedures are to be used as tools to find answers to these questions (De Vos & Strydom, 2011: 35). This information is relevant because the researcher believes that the conceptual framework steers the whole research activity and as such serves as a map or rudder to guide toward realizing the objectives of the study (Regoniel, 2015). The conceptual framework is constructed, not found, and incorporates pieces borrowed from

elsewhere. However, the overall structure is the result that systematically developed from ideas provided from prior exploratory research, existing theory, and the researcher's experiential knowledge (Bickman & Rog, 2009: 223). An important part of the conceptual framework is the research paradigm(s) within which this work is situated. The conceptual framework of this study is introduced in this chapter and sets the stage for the presentation of the particular research questions that drive the investigation being reported based on the contextualization of the problem statement as suggested by Imenda (2014: 190).

1.2. BACKGROUND AND CONTEXTUALIZATION

"Sceptical curiosity" encourages researchers to critically question findings derived from similar research studies and, whenever possible, replicate these findings in different situations with different groups or participants (Grinnell & Unrau, 2008). Prior to embarking on this study and based upon this notion, the researcher judiciously based a needs assessment upon her own and other similar studies. Cuskelly et al (2008: 109) maintain that there is often incongruence between the idealized fathering experience and the actual one; therefore this study sought to obtain data which will help to address this gap for South African fathers of a child with DS.

Altieri and von Kluge (2009: 84), and later, Kayfitz, Gragg and Orr (2010: 337) report that fathers of children with DS have less access to social support than mothers. Such reports are not uncommon, and as a founder member of a family support association thirteen years ago, this was also the researcher's experience. This issue re-emerged was later identified in the findings of her Masters' study, and reappearing again in the findings of the current study. Hence, anticipating a recurring need for focussed father support, the researcher envisages that a platform for fathers may provide a suitable space of giving and receiving, accepting and sharing for those fathers who may feel the need to join such a group. Accordingly, a father chapter can be created. Loosely based on the American model, such a chapter may create a space where fathers can share own insights and concerns, and be a source of reciprocal encouragement as they adapt to their new role as father, specifically as the father of a child with DS.

The scope of this study is wide. Although the focus is on fathers, the father cannot be viewed in isolation, but rather as an individual system functioning within a marriage system, as part of a family system. The theoretical framework of this study rests on the systems theory. Elwell (2013) refers to such systems as being composed of parts that are

interrelated and whose operations have consequences on the whole. To clarify, *parts*, referring not only to each individual member of the family, but also to the individual domains of each member of the family, and how the functioning of each domain of each individual has consequences on both the individual and on the whole family.

In this study, the father is seen as a system which comprises several subsystems namely the emotional, physical, cognitive, behavioural and spiritual subsystems, domains, which are interrelated and impact his overall functioning, as noted by Elwell (2013). Understandably a life-changing event such as becoming a parent of a differently abled child may affect both the intra-personal and inter-personal functioning of every subsystem. These concepts, as well as the concept of interrelatedness and significance to this study are explained in more detail in Chapter Four.

Fatherhood as a research topic traverses an enormous spectrum. Although many relevant and significant aspects of fatherhood are included, realistically the literature reviews are limited to fathering situations restricted to the sampling spectrum. As such, single, absent, step, gay and adoptive fathering situations, as well as specific fathering experiences within various diverse cultural rural communities fall outside the spectrum of this specific study. The researcher implores the reader not to consider this decision as dismissive, but rather as rational, practical and appropriately reasoned.

This section briefly introduces the background of the study and provides context for the reader. The literature chapters provide information relevant to the perspectives of fathers and include background to the syndrome, and aspects dealing with grief, coping, family dynamics and family functioning. In addition to general fatherhood per se, this study also necessitates appropriate historical and contemporary perspectives, theories, approaches and roles pertaining to the father of a differently abled child. Some older sources are used to verify chronological perspectives which the researcher believes to be valuable contributions as a building block for her work; and, albeit dated, these do not compromise the authenticity of this study (Thomson, 2013).

Referring to the touching essay “Welcome to Holland”, which introduces the position of the researcher at the beginning of this thesis, a powerful analogy is drawn between a voyage to an unexpected destination and the birth of a child with an unexpected disorder (Friehe, Bloedow & Hesse, 2003: 220), in this case DS. This analogy accurately describes the perceptions of families of a child with DS; drawing poignant parallels of participation, shared roles of the family members and their responsibilities (King, Baxter, Rosenbaum,

Zwaigenbaum & Bates, 2009: 51). The author, Kingsley (1987), describes the unremitting pain surrounding an altered itinerary involving a differently abled child, especially in comparison to fellow travellers who are raising typically developing children. Not only is the parent and every individual in a family affected, but indeed the entire family dynamic is altered (Hodapp, 2007: 280).

It is not uncommon to view the birth of a child as a happy and exciting occasion to be celebrated by the whole family. However, amongst the list of supposed stress creators in modern lives, few compare in scope and magnitude to the life-altering event of becoming the parent of a differently abled child (Orphan, 2004: vii – xi; 5). Dowling et al (2006: xi; 20) confirm, “One is never quite so alone as the moments after you receive the diagnosis which changes your life, and that of all of your family members, forever.” Fortunately, after the initial shock of their child’s diagnosis of DS, most parents soon discover that the syndrome is entirely secondary to the individuality and uniqueness of their child, that their child has exactly the same needs as every other child, and, that their *unexpected* child in reality brings them much *unexpected* joy and happiness (Orphan, 2004: xi).

It is also not uncommon for parents to develop hopes and dreams about who their baby will be in the world and how they will be as parents. Hence, when their baby is born with special needs, much of what was imagined and planned is forever changed (Reinsberg, 2010; King & Patterson, 2000). Dowling et al (2006: 4) express this grief of parents as the loss of initial hopes, dreams and expectations – essentially a loss of “what might have been.” Reinsberg (2010) confirms that the parents’ profound sense of grief often manifests as symptoms of traumatic stress, particularly at the time of their child’s diagnosis.

Van Riper (2007: 125) cautions that expression of grief may create a highly emotional and stressful environment for the child with DS, the parents and even the siblings. Such a volatile environment may be further compounded by the parents’ inability, or unwillingness, to speak about, or share their specific feelings of grief and loss (Reinsberg, 2010). Parents of a child with DS are known to experience every emotion on the emotional continuum (Van Riper, 2007: 118). Researchers refer to the *paradox of disability* which denotes the melange of conflicting emotions that parents of a child with DS experience on an ongoing basis: pain, despair, suffering and sorrow, yet, also joy, hope, happiness and optimism (Van Riper, 2007: 118; Lam & Mackenzie, 2002: 225) and they believe that the ability of a parent to embrace *this* paradox ultimately enhances parental and family adaptation to their new circumstances. Although grief is the *one* emotion that *every* parent of a differently abled child experiences, O’Leary and Thorwick

(2006: 78) report grief to be the specific emotion which especially fathers frequently seem to disregard or actively hide. Discussion on parents' on-going sense of loss continues in Chapter Three.

Abilities, capabilities, capacities and needs are uniquely individual, whether you have an extra chromosome or not. Equally, the response to having a child with DS is uniquely individual for each parent and family. Some families cope extremely well with rearing a child with DS, while other families, for a variety of reasons, have considerably more difficulty (Singer, 2006: 155). Although the birth of a differently abled child is almost never expected, it almost always necessitates a change in plans as family members adjust their views of their own future, their future with their child, as well as how they will operate as a family given their new set of circumstances (Cuskelly et al, 2008: 105).

Chapter Three expands on the adjustment and coping of families, family dynamics and family functioning, with a focus on aspects relating to the fathering experience of the father of a child with DS. Preceded by a contextualising overview on the etiological background of DS and research history around the fathering experience of fathers of a child with DS, Chapter Three concludes the two literature review chapters on fatherhood.

Many research studies (Takataya et al, 2016; Skotko et al, 2011; Cuskelly et al, 2008; Hodapp, 2007) have documented the dearth of information about families (and especially about the fathers) of children with DS. However, it is encouraging to note that research orientation in the field has notably shifted from "negative" to "stress-and-coping" perspectives (Skotko et al, 2011; Cuskelly et al, 2008; Hodapp, 2007: 279). The ability of mothers, fathers and siblings of children with DS coping slightly better compared to family members of individuals with other disabilities, is attributed to a phenomenon called "Down syndrome advantage" (Skotko et al, 2011: 2336), which is deliberated in Chapter Three.

According to Costantino (2010: 87), an unanticipated life event such as the birth of a differently abled child, inevitably requires lifestyle changes for both the parents and the family, sometimes resulting in a temporary loss of a measure of stability. In times of *just* coping, mothers and fathers may react differently (Paulson & Bazemore, 2010: 1961). For example, some may reach out to friends and family for reassurance and support; some withdraw and go into 'hiding' for a while; some connect closely with spiritual communities and family members; or sometimes either parent merely direct their anger and frustration at whoever is convenient. Frequently, participation in social activities take a backseat to sheer exhaustion and/or logistical challenges, hobbies become neglected, and friendships

are forgone, whilst contact with other adults may become restricted to parents of other differently-abled children met through school or support groups (Dowling et al, 2004: 125; Olsson & Hwang, 2003: 329).

Metaphorically speaking, as a father once remarked, *this* roller coaster neither allows pit-stops nor disembarkation (Webber, 2011). This was reiterated by a participant in a research study by Takataya et al (2016: 5) who said: "...after the birth of my child with DS life itself was severe, and unknowable, like a roller coaster with ups-and-downs." Ironically, amidst this turmoil, society evaluates fathers in terms of the support they give to mothers; whilst in reality, they are themselves often deeply distressed by their child's disposition; questioning their own capability to respond to their child's specific needs; and are, mostly, uneasy about the future of their child (Pelchat, Lefebvre & Perreault, 2003: 232). According to Cuskelly et al (2008), disability is typically viewed as a burden and the general community holds fairly negative views concerning parenting a child with DS. In the past (and frequently even today), professionals maintained low expectations regarding the development and community involvement of children and adults with DS (Buckley, 2002) and as they were seen as a burden to the entire family, parents were often advised to institutionalise their children with DS (Buckley, 2002: 7).

In some cultures it is believed to be "a disgrace to have a child with a disability born into the family" (Cowles, 2003: 13). Roman and Greek cultures viewed persons with physical disabilities as burdens on society and therefore less than human (Gordon, Feldman, Tantillo & Perrone, 2004). Raising a child within a community that sees disability as a tragedy can be stressful (Mathembane, 2016: 169).

Sagahutu and Struthers (2014: 154) reveal that, amongst many of the South African ethnic cultural groups, having a child with DS is often perceived as an ancestral curse which leads to stigmatization of both child and family members, and regularly results in the children with DS being hidden from society, and commonly subjected to harsh living circumstances. In some cultures persons with DS may be accepted, but are hidden for fear of discrimination against the family members, or retaliation against them for bringing 'bad luck' to a tribe or community (Munyi, 2012). Some communities have not progressed as far as others in changing negative beliefs and negative attitudes, and parents and families will be influenced profoundly by such views, according to Ovens (2009: 2).

The situation is further compromised by the reluctance of most men to engage in personal, family or couples therapy, or to seek help for physical or psychological problems

when they experience problems in coping with emotionally charged situations such as, in this case, having a child with DS (Pelchat et al, 2003: 233). Because it is not uncommon for mother and child to receive all the attention immediately following the diagnosis of the child, the false perception is easily created that the father is dealing with the diagnosis on his own, or that he does not require as much attention to process this news or come to terms with it. Consequently, as everyone around the father just expects him to cope, this is what fathers attempt to do (Orphan, 2004: 110).

Boström and Broberg (2014: 811) agree that father-child interaction represents an essential resource for child development. The past decade has seen a surge of research and interest in fatherhood with an increased recognition that involvement of fathers contribute to the well-being, cognitive growth and social competence of their children (Flippin & Crais, 2011; Dyer, McBride, Santos & Jeans, 2009). A comprehensive discussion on the significance of the father role follows in Chapter Two. However, if the father has *not* reached a place of 'peace' and acceptance, this formidable charge may seem intimidatingly arduous and frightening (Dabrowska & Pisula, 2010: 275).

Cuskelly et al (2008: 107) attribute a family's ability to move forward to certain essential adjustments. These are: the acceptance of their new reality; adopting a different set of values based on the inherent worth of every individual; and their focussing on strengths rather than weaknesses of each family member. Brown, Mac Adam-Crisp, Wang and Iarocci (2006: 239) argue that how these specific issues are embraced and managed may dramatically influence the peace and harmony of family life.

Research has shown that maternal stress mostly relates to the parenting role and the demands of child care, while paternal stress was found to be more related to the father's feelings of attachment to the child and to the child's social acceptability (Keller & Honig, 2004: 338). Although it takes a very determined parent to maintain a sense of balance and normality in their family's life once there has been a diagnosis, Van Riper (2007: 117) argues that the benefits are enormous and suggest that parents (especially fathers), often require help and support to grow to be emotionally, physically and spiritually available for this role. Cuskelly et al (2008: 107) verify that greater parenting efficacy has been associated with increased positive perceptions of the child with DS. Relating to this situation, parent efficacy refers to the individual's level of confidence in their parenting, that is, the confidence that they possess the skills to provide the necessary guidance for their child, and confidence that theirs is a satisfactory parenting role (Teti & Gelfand, 2008).

1.3. PURPOSE OF THE STUDY

This study has a two-fold aim: firstly, to gain insight and a better understanding of the perceptions, perspectives and experiences of South African fathers of a child with DS, and second, the exploration of a viable means to enhance this experience. Fouché and De Vos (2011: 95) concede that, although one objective is usually dominant, studies may have multiple objectives.

As a research goal, the researcher determined this study to encompass exploratory, descriptive and intervention research elements, justified as follows. Firstly, exploratory research as described by Blaikie (De Vos et al, 2011: 95) in terms of gaining insight into a situation, phenomenon, community or individual, by answering the “what” questions (Mouton, 2003: 53) – in this case gaining insight about both general fatherhood, and the more specific phenomenon of being the father of a child with DS. Secondly, descriptive research as it presents specific details of a situation, social setting or relationship, with a focus on “how” and “why” questions (Kreuger & Neuman, 2006: 23) related specifically to this unique fatherhood experience.

To this end, the researcher aims toward a more intensive examination of this phenomenon and its deeper, personal meaning for the fathers, as suggested by Rubin and Babbie (2008: 125). Lastly, this study also contains an intervention research aspect as it endeavours to shed light on, and provide a possible solution to a practical problem (De Vos et al, 2011: 98), that being the vision toward a supportive platform for fathers of a child with DS if needed.

The intention of the researcher is to contribute positively and significantly toward the current limited existing body of knowledge of especially a specific group of South African fathers of children with DS.

1.4. FORMULATION OF RESEARCH PROBLEM

As an effective point of departure for this study, the researcher considered three important factors which underpin the process of formulating the research problem, namely, a relevant literature review, the unit of analysis, and the research objective. As suggested by Monette et al (2008: 81), the researcher accessed relevant literature to become more familiar with the current state of knowledge regarding the research problem, to narrow the focus of the study, to learn how other researchers delineated similar issues, and, to

ensure that previous studies were not unnecessarily duplicated. The researcher also considered the unit of analysis best suited to the research objective, referring to the participants from whom and about whom data would be collected (Monette et al, 2008: 83).

The problem statement is based on the context (See section 1.2) and the issues that motivated the researcher to conduct the study. Evident from the background to this study, most research on parenting of a child with DS has been focussed on mothers, and despite the explosion of research into the role of the father, little research has been carried out with fathers of children with DS or any other similar condition. Research focussing solely on fathers of children with DS is almost non-existent.

In order to assess how to fill the gap for this cluster of fathers, the following questions were formulated for this study.

1.4.1. Primary Research Question

How are the fatherhood perceptions, perspectives and experiences of South African fathers of a child with DS impacting their parenting experience?

From the primary research question, the following secondary questions were derived:

1.4.2. Secondary Research Questions

- *What are the challenges presented to South African fathers of a child with DS with regards to their parenting experience?*
- *How do South African fathers perceive the personal implication of being the father of a child with DS?*
- *How may an effective platform of support contribute toward an enriched fathering experience for South African fathers of a child with DS?*

The answers to the aforementioned questions will become clear upon analysis of gathered data.

1.5. RESEARCH OBJECTIVES

Based upon a review of the literature relevant to the research question and the accuracy and truthfulness of issues identified by participants in order to be of value to most fathers of children with DS, the following research objectives have been formulated:

1.5.1. Primary Objective

To determine how the fatherhood perceptions, perspectives and experiences of South African fathers of a child with DS are impacting their parenting experience.

1.5.2. Secondary Objectives

- *To establish what challenges are presented to South African fathers in the parenting experience of their child with DS.*
- *To explore how South African fathers of a child with DS perceive the personal implication of being the father of a child with DS.*
- *To investigate how an effective platform of support for South African fathers of a child with DS may contribute toward an enriched fathering experience.*

1.6. DEMARCATION OF THE STUDY

Qualitative research, following a phenomenological approach, was undertaken. This method was deemed most appropriate as it allowed the researcher to study the meaning fathers hold in relation to their experiences of their world. Sources of information include relevant and significant literature related to fatherhood, the fathering experience in general, and more specifically, as experienced by fathers of children with DS. Consideration of selected theories on fatherhood, the traditional roles of fatherhood, as well as the consequence of effective fatherhood are included in a comprehensive literature study in support of the practical research and analysis.

Data were generated by means of self-reports in response to questionnaires. The population for this study includes South African fathers of any age, income, culture or ethnic group; who either have or have not; and are, or are not experiencing challenges in their experiences, perspectives or perceptions regarding the fathering of their child with DS of any age or gender. Thematic data analysis was applied.

1.7. CLARIFICATION OF CONCEPTS

- **Down syndrome**

DS is the most common genetic cause of significant intellectual disability in the human population. It is a chromosomal condition characterized by the presence of an extra copy of genetic material on the 21st chromosome, either in whole (trisomy 21) or part (such as due to translocations). **Down** refers to the surname of Dr John Langdon Down, who in 1886 recorded the characteristics that set a specific group of patients apart from others with a 'mental handicap' (intellectual impairment) (Down syndrome South Africa, 2010).

The term **syndrome** implies a collection of characteristics and symptoms "resulting from a common cause or appearing in combination, to present a clinical picture of a disease or inherited abnormality" (Mosby's Medical Dictionary, 2013). This term is used to refer to children who are born most commonly with 'Trisomy 21' (meaning three copies of chromosome 21). To a lesser extent, children are born with a translocation form of the extra chromosome, where the extra chromosome 21 is attached to one of a different chromosome pair. Small numbers of children have mosaic DS, where only some cells are trisomic and affected (DSSA, 2010).

DS is a genetic disorder that includes a combination of birth defects including some degree of intellectual impairment, characteristic facial features and, often, heart defects, visual and hearing impairment and other health problems. Severity of these problems varies greatly among affected individuals. It is one of the most common genetic birth defects, affecting approximately one in 800 babies worldwide. According to Down syndrome South Africa (DSSA), the prevalence of babies born with DS in South Africa is currently one in every 550 live births (DSSA, 2010).

To understand why DS occurs, the structure and function of the human chromosome must be understood. The human body is made of cells; all cells contain chromosomes, which are structures that transmit genetic information. Most cells of the human body contain 23 pairs of chromosomes, half of which are inherited from each parent. Only the human reproductive cells, the sperm cells in males and the ovum in females, have 23 *individual* chromosomes, not pairs. Scientists identify these chromosome pairs as the XX pair, present in females, and the XY pair, present in males, and numbered them 1 through 22 (Patterson, 2009).

When the reproductive cells, the sperm and ovum, combine at fertilization, the resultant fertilized egg contains 23 chromosome pairs. A fertilized egg that will develop into a **female** contains chromosome pairs 1 through 22, and the XX pairing. A fertilized egg that will develop into a **male** contains chromosome pairs 1 through 22, but in a XY pair. When the fertilized egg contains extra material from chromosome number 21, this results in DS. Most people have normal cell structures, which are arranged in 23 chromosomal pairs, resulting in 46 chromosomes, but a person with DS has 47 chromosomes (Patterson, 2009).

All people with DS are individuals with individual talents and abilities. The effects of the extra copy vary greatly among persons with DS. The only thing they have in common is the syndrome itself. Much has been accomplished to overcome the medical conditions confronted by persons with DS, resulting in increased quality of life and life expectancy. Significant cognitive improvement has been achieved by enhancing the educational and social opportunities of persons with DS, offering hope that additional progress is possible (Patterson, 2009).

- **Typically developing**

This term refers to children who progress through the different developmental stages without obvious delays in the many social, physical and cognitive aspects of the phases of development and who do not manifest special educational needs. The term 'normal' is offensive since it implies that a child with special needs is 'abnormal'. It is often in contrast to 'typically developing' children that one can best describe the needs of children who face challenges such as DS (Webster, 2010).

- **Differently abled**

While doing research for a Masters' degree on the impact on the family dynamic of having a child and a sibling with DS, the researcher elected to substitute the terminology "disabled" with her own semantic conviction "differently abled". This terminology is applied throughout this study in support of the researcher's conviction in the ability of all individuals, however different those may be. According to Cartwright (Swartz, de la Rey, Duncan & Townsend, 2011: 471), terminology such as "disabled" is frequently, incorrectly and insensitively applied, constituting labelling with a negative connotation. The term *disability* is only used in this study where deemed absolutely necessary; mostly in

reference to the global term 'disability' or for semantic accuracy (World Health Organization, 2012)

- **Intellectual disability**

Intellectual disability (ID) is a disorder that has enormous social effects; not only does it affect the individual with ID, but also the family and society as a group. Defined by World Health Organization (2012), ID is "a disorder defined by the presence of incomplete or arrested mental development, principally characterized by the deterioration of concrete functions at each stage of development and that contribute to the overall level of intelligence, such as cognitive, language, motor and socialization functions; in this anomaly, adaptation to the environment is always affected. For ID, scores for intellectual development levels must be determined based on all of the available information, including clinical signs, adaptive behaviour in the cultural medium of the individual and psychometric findings."

Causal factors related with cognitive disability can be classified as genetic, acquired (congenital and developmental), environmental and sociocultural (Katz & Lazcano-Ponce, 2008: 132). Genetic factors refer to chromosomal or hereditary disorders, with the greatest number of patients being individuals with DS (Määttä, Tervo-Määttä, Taanila, Kaski & Iivanainen, 2006: 38). The common denominator in cognitive disability is a subnormal intellectual functioning level; however, the extent to which an individual is unable to face the demands established by society for the individual's age group has brought about four degrees of severity: mild, moderate, severe and profound.

According to Määttä et al (2006: 39), diagnosis of ID rests on numerous factors and may include the following procedures: a comprehensive clinical history with emphasis on healthcare during the prenatal, perinatal and postnatal period, including results of all previous tests. Testing procedures should also include a genealogical tree for at least three generations and an intentional search for family antecedents of mental delay, psychiatric illnesses and congenital abnormalities. A physical exam should focus on secondary abnormalities and congenital malformations, somatometric measurements and neurological and behavioural phenotype evaluations. Määttä et al (2006: 39) further suggest that if it is not feasible to establish a clinical diagnosis, high-resolution cytogenetic studies can be conducted in addition to metabolic clinical evaluations. Submicroscopic chromosomal disorders are evaluated if no abnormal data are identified.

Määttä et al (2006: 39) remind us that ID is not curable. When using the emotional wellbeing of the individual as a parameter, the prognosis is generally good. ID should be treated in a comprehensive manner. Once ID has been identified, it is important to provide the necessary support in areas of strengths and weakness in each one of the dimensions in which the individual's life is exposed and expressed, according to the individual's age and future expectations.

- **Fatherhood**

The concepts of fatherhood and fathering are inextricably linked and often applied interchangeably. However, Doucet (2007: 192) draws the definitive distinction between fathering and fatherhood as follows: “*Fathering* refers to how men perceive, live out and enact practices of fathering while doing so within the larger political, social, cultural, symbolic, ideological and discursive institutions of *fatherhood*.”

Englar-Carlson (2011) describes fatherhood as a socially constructed role that mirrors the definition and ideas of a particular culture and society; however, due to the pluralistic realities in contemporary society, a degree of uncertainty remains about the definition of the *ideal* father. Although the common law presumption is that the husband of a married woman is the genetic father of any child she bears, paternity can be established with a high degree of accuracy. With regard to the question around “who is the legal father” (as this has been complicated by developments in reproductive technology and ‘new’ family norms), Collier (2008) recognizes that different men may share the legal rights, responsibilities, and status of fatherhood and play important roles in a child's life.

The importance of family and the nature of the role of the father are likely to vary across cultural groups, and although historically fatherhood has entailed ideas of men as breadwinners and providers for families rather than carers and nurturers of children, research suggests this may be changing (Englar-Carlson, 2011). As many men seek a more ‘involved’ relationship with children, the rights and responsibilities of fathers has become an increasingly contested issue in law reform debates, in particular in the area of post-divorce contact and residence arrangements (Collier, 2008).

- **Fathering**

In order to adapt to the changing economic, social, and cultural needs, fathering practices have changed significantly over the past two decades. According to the Encyclopaedia on

Early Childhood Development (2015), relative to a few decades ago, mothers are more likely to work outside of the home, thus requiring fathers to become increasingly engaged in the daily care of children. In addition, attitudes towards gender roles and expectations have also evolved over the years, in turn allowing fathers to play a more active role as caregiver and a key role in the development of children by promoting their identity, cultural values, safety, social-emotional competence, and school readiness. With regard to the increasing evidence that a father's physical location and child involvement are two completely separate dimensions in the father-child relationship, Fox, Nordquist, Billen and Savoca (2015: 462) note that father absence does not automatically mean lack of involvement, and by the same token, mere presence does not always guarantee father engagement.

- **Parenting**

Literature on parenting is voluminous and it is no secret that parenting powerfully influences a child's well-being (Brooks-Gunn & Markman-Pithers, 2005: 139). Drawing a simplistic distinction between the mothering role that leans broadly to care and affection, and the care given while fathering leaning toward the protective, Milton (2015) concedes that parenting (roles) are simultaneously challenging, tedious and rewarding. Whilst these roles are exchanged and interchanged in most parenting situations, the parenting role per se can be seen as the umbrella term for the collective of both the mother and the father fulfilling all these roles in tandem. As parenting and mothering are not the main focus of this study, this succinct clarification will suffice.

- **Ontological**

The word ontological derives from Greek, *onto* (being) and *logia* (written or spoken discourse, and as a branch of metaphysics, refers to the study of the nature of existence or the essence of things (Mason, 2002). Succinctly stated, ontology amounts to the study of anything and everything, what is involved in its existing, and further, the commonalities shared by such social entities. Ultimately the value of ontology lies in providing clarity and directionality. As such it provides insight into the nature of that which is being investigated or expressed. Lawson (2004) clarifies the distinction between the following closely linked concepts in research: *ontology* refers to ways of constructing reality, "how things really are" and "how things really work", in other words, the study of what *is*, or what exists; *epistemology* refers to different forms of knowledge of that reality, what nature of

relationship exists between the inquirer and the inquired? How do we know; and *methodology*: What tools do we use to know that reality?

- **Epistemological**

Defined narrowly, epistemology is the study of knowledge and justified belief (Steup, 2014: 1). According to Vasilachis de Gialdino (2009), epistemology raises questions such as: how reality can be known; what is the relationship between the *knower* and what is *known*; what are the characteristics, the principles and the assumptions that guide the process of knowing, as well as the achievement of findings; and, what is the possibility of that process being shared and repeated by others and how then can it contribute to assess the quality of the research and the reliability of those findings.

As the study of justified belief, epistemology aims to answer questions such as: How are we to understand the concept of justification? What makes justified beliefs justified? Is justification internal or external to one's own mind? Understood more broadly, epistemology is about issues having to do with the creation and dissemination of knowledge in particular areas of inquiry (Steup, 2014: 1), such as the social reality which is the basis of this study.

- **Phenomenology**

According to Waters (2015), the goal of qualitative phenomenological research is to describe a "lived experience" of a phenomenon. *Phenomenological research* involves trying to understand the essence of a phenomenon by examining the views of people who have experienced that phenomenon. Phenomenology is interested in the individual experiences of people. In-depth interviews with participants usually provide a full picture of their experience with the phenomenon. A phenomenological researcher will scrutinize interview material for patterns. Essentially, phenomenological research is looking for the universal nature of an experience. Two of the main strengths of phenomenological research are that it provides a very rich and detailed description of the human experience, and secondly, that the results emerge from the data, rather than being imposed by a structured statistical analysis.

1.8. RESEARCH DESIGN

According to Thomas (2009: 70), the research design is the plan that shows how a researcher intends to explore a research problem, and the aim of the research design is to make sure that the data gathered will play a role in answering the research question(s) as accurately as possible. Due to the nature of this study, the application of exploratory, descriptive and interpretive research designs are justified as follows: It is exploratory as it provides insights into and comprehension of an issue or situation that has not clearly been defined (Streb, 2010: 373); as descriptive research it describes the perspectives, perceptions and experiences of fathers of a child with DS and answers the who, what, where, when and how questions; and interpretive insofar as it describes multiple views of reality, and takes into consideration the subjective meanings that fathers in such situations bring into their world (Creswell, 2014: 182).

The researcher's point of view is but one of many and it is important for the researcher to make his role explicit (Creswell, 2007: 147). The researcher interprets the data, studies the participants in their natural environments, while attempting to understand and interpret phenomena. This includes the development of a description of a person or a setting; analysis of data for themes; and finally, the drawing of conclusions. In this study the focus will be on the interpretation of what fathers have expressed in terms of their perspectives and experiences of having a child with DS.

1.8.1. Philosophical Paradigm

The researcher's philosophical paradigm is informed by her ontological and epistemological orientation. Trochim (2006) argues that phenomenology is sometimes considered a philosophical perspective as well as an approach to qualitative methodology. With a long history in several social research disciplines including psychology, sociology and social work, phenomenology is a school of thought that emphasizes a focus on people's subjective experiences and interpretations of their world.

The researcher's point of departure for this study is to understand people (Babbie, 2007: 28) and how the world appears to them (Trochim, 2006), rather than mere mechanical establishment of facts predominant in a quantitative paradigm. The researcher's ontology (view of reality) is rooted in an empathetic better understanding of the everyday lived experience of the participants (Neuman, 2009: 5) and as such incorporates an improved understanding of the perspectives and the perceptions of fathers of a child with DS. The

researcher's ontology is reflected primarily in the given of the researcher's belief that reality is only known by those who experience it personally. However, the researcher also maintains a phenomenological perspective which maintains that all human beings are engaged in the process of making sense of their worlds and continuously give meaning, interpret, justify and define their actions (Babbie, 2007: 28).

In line with this, the philosophical underpinning of this study hinges on the following. Firstly, it's relevance to the researcher's interest in DS, and, ultimately, relevance to the interest of families affected by DS as the researcher interprets the meaning that research participants give to their life world (Schwandt, 2007: 315). Secondly, once the phenomenon is understood, the opportunity to address any specific needs emergent from this interpretation (Cameron, Schaffer & Hyeon, 2001: 432). Lastly and most importantly, as documented by Creswell (2007: 57) as the root of phenomenology, is the researcher's profound intent to understand the phenomena under study in order to provide a discerning description of human experience as experienced by the participants themselves.

Thus, this study, albeit focussed on fathers, is essentially directed toward enhancing existing knowledge about DS (Fouché & De Vos, 2011: 87). The fundamental philosophical question driving this research is in essence more a statement, namely, to seek deeper *significance* of the fathers' experience in order to launch a *significant* plan of action which could *significantly* enrich *their* fathering experience of their child with DS.

The researcher's ontological standing is also reflected by the analogy "Welcome to Holland". Although not all fathers may equally or similarly be affected by *landing in a different country*, such an *unexpected change in destination* certainly does affect them in the traditional role of leader, provider, plan-maker, fixer and protector of their family. As a phenomenological study attempts to understand people's perceptions, perspectives and understanding of a particular situation, the researcher's focus of this study is on the individual *human experience* of fathers of children with DS.

To this end, research questions are based upon the lived experience of the people who experience it first-hand (Leedy & Ormrod, 2005: 140) which also underpins the epistemological orientation of the researcher. Although the study is not primarily phenomenological, some of its aspects are underpinned by the principles of phenomenology which focuses on discovering and expressing essential characteristics of a certain phenomenon as they really are.

Epistemology entails a general set of assumptions about the best ways of inquiring into the nature of the world. Mason (2002: 16) defines epistemology as follows: “Questions about what we regard as knowledge or evidence of things in the social world are epistemological questions and, overall, are designed to help you to explore what kind of epistemological position your research expresses or implements.”

Based on Baptiste’s (2001) epistemological views when searching for truth, the researcher believes that her understanding of the experiences and perspectives of South African fathers of a child with DS increases exponentially once she appreciates how fathers experience it and understand the meanings they ascribe to it. To this end, the researcher relied on their viewpoints and expressions to build a suitable knowledge base about this phenomenon (Baptiste, 2001). The researcher believes that all people are socialised in particular ways, which affect how they perceive and interpret their world, and that their norms, values and beliefs are moulded in the social context in which they were brought up. Thus, the researcher includes the epistemological notion of constructionism (Crotty, 2005).

The researcher leans to the constructivist ontological assumption of subtle realism proposing that reality exists, however that this reality cannot be known accurately, only what it means to those who are a part of it (Fouché & Schurink, 2011: 310). Aptly described by Crotty (2005: 45), “no object can be adequately described in isolation from the conscious being experiencing it, nor can any experience be adequately described in isolation from its object.” Since we enter a world of meaning that already exists by birth, it is important to take cognizance of social constructionism. This world includes symbols of meaning, such as beliefs, values, and norms found in the particular social structures we found ourselves in, like culture, community, and family and serve as “...interpretative strategies whereby we construct meaning” (Crotty, 2005: 53).

Within this context, the researcher believes that reality is created as we live it day by day. Thus the researcher views reality and social world not as static, but as forever changing. A constructivist epistemology further extends to the belief that neither detached or entirely objective stance can be adopted by the researcher, since together with the research participants, the researcher co-creates what is being studied (Glicken, 2003: 31).

1.8.2. Theoretical Framework

In general, both 'conceptual' and 'theoretical' frameworks refer to the epistemological paradigm a researcher adopts in looking at a given research problem, as Liehr and Smith (1999: 12) point out, "each of these terms refers to a structure" which guides the researcher. The research problem (see Section 1.4) anchors this study and forms the basis from which the theoretical framework is constructed (Lynham, 2002).

Imenda (2014: 189) argues that the theoretical framework is the theory researchers choose to guide them in their research, and as such views a theoretical framework as the application of a theory, or a set of concepts drawn from one and the same theory, to offer an explanation of an event, or shed some light on a particular phenomenon or research problem. Weick (2014) adds that a theoretical framework is used to limit the scope of the relevant data by focusing on specific variables and defining the specific viewpoint that the researcher will take in analysing and interpreting the data to be gathered. It also facilitates the understanding of concepts and variables according to given definitions and builds new knowledge by validating or challenging theoretical assumptions.

The researcher selected the systems theory as a means by which to identify the themes emergent from the data in order to define the research problem and to maximize understanding of the issue under research. The researcher believes the use of the systems theory is not only deemed a suitable means to interpret new meaning regarding the perspectives, perceptions and experiences of fathers of a child with DS, but also as feasible a means of providing members of a professional discipline with a common language and a frame of reference for defining the boundaries of their profession, as well as a practical means to guide and inform research so that it can, in turn, guide research efforts and improve professional practice (Weick, 2014).

According to Mele, Pels and Polese (2010: 126), systems theory is "an interdisciplinary theory about every system in nature, in society and in many scientific domains, as well as a framework with which phenomena can be investigated from a holistic approach." Thus, in systems thinking, the shift in attention is from the part to the whole. Employing the basic systems theory as conceptual framework for this study is based on the researcher's opinion that every domain (emotional, physical, cognitive, behavioural and spiritual) of the father is impacted by this life event, that the domains impact each other, that this impacts how the father functions internally, and that his outward expression is driven by this

internal manifestation. Furthermore, this internal manifestation and external factors affect each other reciprocally.

Using the definition of Ng, Maull and Yip (2009) to further explain: a system, in this case, can be defined as an entity (the father), which is a coherent whole (made up of father's different intra-psychic domains: emotional, physical, cognitive, behavioural and spiritual) such that a boundary is perceived around it in order to distinguish internal and external elements and to identify input and output (related to the father's experiences, perspectives and perceptions of the life event), relating to and emerging from the entity (in other words, that which he experiences internally is influenced by external factors, and conversely, he then reacts outwardly according to what he is experiencing internally). The focus of this study is on the interactions and on the relationships between parts in order to understand the entity's organization, functioning and outcomes (Mele et al, 2010: 126).

Historically socio-ecological models were developed to advance the understanding of the dynamic interrelations among various personal and environmental factors. Renowned ecological-systems approach of Bronfenbrenner (1994) understands vulnerability as being influenced by multiple contexts. These contexts are broadly categorised into four levels, namely the individual or intra-personal level and the inter-personal level (microsystem), the community level (mesosystem) and the societal level (exosystem). Social, political and economic conditions are themselves influenced by the general beliefs and attitudes (macrosystems) shared by members of the society (McLaren & Hawe, 2005).

Appropriate to this study, an ecological-systems approach to understanding the father's experience emphasises the interdependence between these factors across all levels (Govender, Petersen & Pillay, 2011: 401). Bronfenbrenner (1989) later developed the bio-ecological model after recognizing that individual functioning was overlooked in other theories of human development. As a lifespan approach to development, the bioecological model of human development can be applied to both children and maturing adults.

Acknowledging that systems theory spans a vast spectrum, the researcher elected to limit this discussion to pertinent information relative to this study. The basic premise of systems theory is the constant flow of cybernetic energy between all the subsystems, both internally and externally. As these subsystems interdependently influence each other, a change in one system causes the others to adapt.

The constant flow of cybernetic energy is a requirement for the system to survive and this can only happen if there is equilibrium within this system as a whole (Friedman & Neuman-Allen, 2015: 8). Applicable to this study, it can reasonably be assumed that a multitude of extrinsic factors such as family, economics, community and culture may contribute to the perspective, experience and effect that his child's diagnosis has on the father.

The term intrapsychic derives from the Greek "psyche" meaning "soul", in this context, "mind", and Latin intra meaning "within", and the intrapsychic perspective, constituting an early development in the history of psychology, relates to the assumption of the processes within the individual's mind (Phipps & Vorster, 2011). Freud's psychoanalytic approach in the late 1800s was one of the first to incorporate this perspective, according to which there are specific unconscious psychological processes - referred to as the id, ego, and superego - all of which determine an individual's behaviour. Freud's theories are revisited in Chapter Two.

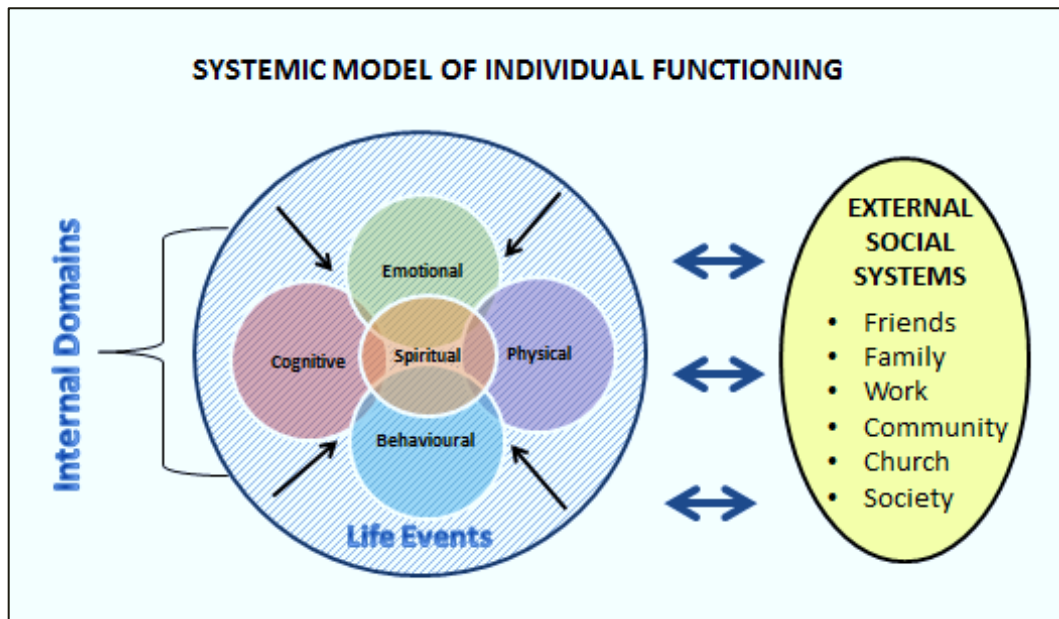
After Freud, psychotherapists tried to uncover additional unconscious processes, a development broadly referred to as the psychodynamic approach. Having explored the unconscious terrain of the mind, they turned increasingly to that of the conscious mind. Common to all these developments is that they share an intrapsychic emphasis: an attempt to understand the mind or subjective experience of the individual (Naidoo, Townsend & Carolissen, 2011: 120-134). An inevitable limitation of the intrapsychic perspective is that we cannot see the mind "at work." Thus, conclusions reached about another individual's mind or subjective experience, are speculative; there is no way of verifying them (Phipps & Vorster, 2011).

As mentioned earlier, relationships of sub-systems influence the overall performance of the system. These interdependent and interrelated relationships influence the overall state of the system at any given moment in time (Sawyer, 2005: 2; 96). To illustrate the systems perspective on individual functioning, the researcher adapted the 1981 model of Hultsch and Deutch to show relevance of how each of the sub-systems (personal development, internal/intra systems and external systems) is significant to the father in terms of his experiences, perspectives and perceptions around raising his child with DS.

The model illustrates how this life event (and other significant life events) impacts the emotional, cognitive, physical, behavioural and spiritual domains of the father (his internal domains); how each individual domain, more than one, or the entire group of internal

domains respond to external social systems; or are individually or as a whole, influenced by his response to external social systems at any given time, depending on his level of individual functioning resultant from specifically this life event and the degree to which it affects his cognitive, emotional, physical, behavioural and spiritual functioning at any given time.

FIGURE 1.1: Researcher’s adaptation of the systemic model of individual functioning



(Adapted from Hultsch and Deutch,1981)

Application of this systemic model of individual functioning is as follows:

The circle with diagonal blue lines signifies the *personal developmental history* which comprises both normative and non-normative events. Normative events would include developmental milestones, going to school and university, getting married, having children, and so forth.

Non-normative events include any idiosyncratic events that occur which may influence the development of the individual, for example own parenting experiences, social interaction experiences with individuals across a broad spectrum of personalities and/or abilities, becoming the father of a child with DS at age 35, and so forth. All events which take place during this period shape and influence the individual at their current age, indicated by the coloured collective circular sections in the middle of the largest blue circle marked life events.

The *internal domains* represent the *intrapersonal system* and are indicated by the coloured circles section in the middle. The intra system comprises of the following domains: physical domain, cognitive domain (perception, reasoning, thoughts and intellect); emotional domain (expressive, responsive, feelings); behavioural domain (conduct, actions, motivation and choices); and, the spiritual (existential) domain (meaning, purpose, resolve, religious, moral development, world view, and so forth). The *external systems* are identified in the yellow oval as social systems such as family, friends, work, community, church, society and such like.

The *directional arrows* signify the basic premise of the systems theory: the constant flow of cybernetic energy between life events and all the sub-systems, both internally and externally and to the system. At all times the interdependent influence causes change in one sub-system (domain) to cause the others to adapt. This system has to survive and it can only survive if there is equilibrium within this system as a whole. Equilibrium in this case would refer to the father's understanding of his internal landscape, what it could be influenced by, and what it could influence in turn, in order for him to have a realistic expectation and experience of fathering his child with DS.

The following section introduces the researcher's research approach, research design and research methodology which will be explained thoroughly in the methodology chapter, Chapter Four.

1.8.3. Research Approach

From the two recognized approaches to research (quantitative and qualitative), the researcher selected the qualitative approach as best suited to this research project. Both approaches have its own characteristics, purpose, methods of conducting the research, strategies for data collection and analysis, and criteria for judging quality (Creswell, 2007: 37-39; Kumar, 2005: 12; Leedy & Ormrod, 2005: 94-97). Drawing a table to compare the differences between qualitative and quantitative research enabled the researcher to select the qualitative approach as best suited for this study.

TABLE 1.1: Differences between quantitative and qualitative approaches

Quantitative approach	Qualitative approach
Epistemological roots in positivism	Epistemological roots in phenomenology
Purpose: testing predictive and cause-effect hypotheses about social reality	Purpose: constructing detailed descriptions of social reality
Methods utilise deductive logic	Methods utilise inductive logic
Suitable for studies of phenomena which are conceptually and theoretically well developed; seeks to control phenomena	Suitable for studies of a relatively unknown terrain; seeks to understand phenomena
Concepts are converted into operational definitions; results appear in numeric form and are eventually reported in statistical language	Participants' natural language is used in order to come to a genuine understanding of their world
Research design: standardised according to a fixed procedure and can be replicated	Research design: flexible and unique and evolves throughout the research process. No fixed steps that should be followed. Design cannot be exactly replicated
Data obtained systematically and in a standardised manner	Data sources are determined by information richness of settings; types of observation are modified to enrich understanding
The unit of analysis is variables which are atomistic (elements that form part of the whole)	The unit of analysis is holistic, concentrating on the relationships between elements, contexts, etc. The whole is always more than the sum.

(Adapted from Fouché and Delpont, 2011: 66)

The choice of research topic was the main determinant for selecting the qualitative approach (Fouché & De Vos, 2011: 90), given this study is epistemologically rooted in phenomenology insofar its intent to understand the phenomenon under study and to provide an in-depth description of human experience as experienced by several participants (Creswell, 2007: 57).

Given that relatively few studies focus on fathers of a child with DS, participants' verbatim responses add authenticity to this process toward a deeper understanding of their experience. Inductive reasoning guided the researcher to begin with a broad topic, DS, refined it to the impression that fathers' experiences and perspectives differed from that of mothers (as gathered from relevant literature), and in analysing the data, refined and elaborated into more exact theoretical concepts (Neuman, 2009: 60). Leedy and Ormrod (2005: 32) state that in inductive reasoning, researchers use specific occurrences or

instances to draw conclusions about the population from which the sample comes. Neuman (2009: 60) argues that conclusion is not completely certain or sure, but only tentative or possible. Thus, although inductive reasoning sees the shift is from the particular to the general (Babbie, 2007: 49), the conclusion is a tentative generalisation (Neuman, 2009: 60). As the current research is focussed on perceptions and conceptualization of the father of a child with DS, the intent is to show specific relevance as opposed to generalization of the fatherhood experience per sé.

Although deductive reasoning is favoured by quantitative researchers (Leedy & Ormrod, 2005: 31), applicable to this study, Neuman (2009: 59) states that deductive reasoning is also used in qualitative studies with the researcher beginning with an abstract concept that outlines the logical connection among concepts and then moves toward concrete empirical evidence. As the intention is to develop new knowledge, the inductive approach is suitable to this study (Trafford & Leshem, 2012: 94). The following table outlines the characteristics of the quantitative and qualitative approaches.

TABLE 1.2: Characteristics of the quantitative and qualitative approaches

Quantitative characteristics	Qualitative characteristics
Measurement of objective facts	Construction of social reality, cultural meaning
Focus on variables	Focus in interactive processes, events
Reliability as the key criterion of scientific excellence	Authenticity as the key criterion of scientific excellence
A value-free stance	Present and explicit values
Research conducted independently of context	Situationally constrained
Many cases or subjects involved	Few case or subjects involved
Statistical analysis the method of choice	Thematic analysis the method of choice
Researcher maintains detached attitude	Involvement of researcher

(Adapted from Kreuger and Neuman, 2006: 16)

Decisive characteristics for selecting the qualitative approach were, firstly, data for this study involving words, descriptions or narratives, and second, the concern with understanding and subjectively exploring the participants' reality from the perspective of an insider. This contrasts with quantitative research which is primarily concerned with

explanation, numbers, counts and measures of things, and maintains an outsider perspective (Monette et al, 2008: 87). Though some researchers regard qualitative data as immaterial and intangible, this approach is ideal for investigating complex topics such as the understanding continuity and change in family development (Neuman, 2009: 328), and is therefore appropriate for this study.

Although the primarily interpretive phenomenological approach of this study supports the researcher's attempt to understand what it is like to stand in the shoes of the participants (albeit recognizing this is never completely possible), Pietkewicz and Smith (2014: 9) caution the researcher to bracket any preconceptions and allow the phenomena to speak for themselves. A phenomenological approach provided the researcher with a suitable research strategy to help bracket (restrict) her biases as well as those of the participants and to conduct the research in an open-minded way by directing all questions at the meaning of participants' experiences, feelings and perspectives about the theme in question (Flick, 2006: 22). Bracketing is discussed in Chapter Four under validity of the study.

The researcher believes that there is value in sharing the evolution of the research questions of this study. The researcher deductively formulated research questions very early in the process. However, after defining her philosophical orientation and clarifying the intention to interpret meaning from experience, the researcher recognised that the eclectic scope of the approach (combining phenomenology, and aspects of interpretive and constructionist approaches), helped refine the research questions, participant selection criteria, and method of data collection. The primary research question changed from: *How can South African fathers of a child with DS be supported to derive optimally from their parenting experience?* to *How are the fatherhood perceptions, perspectives and experiences of South African fathers of a child with DS impacting their parenting experience?*

While this interrogative shift may appear minor, it created a powerful emphasis on the lived experiences of participants, framed broadly and openly, further encouraging the researcher to explore how participants perceive their situations (Smith & Osborn, 2003). This also enabled clarification of the participant selection criteria. Purposive sampling techniques ensured a homogenous sample of participants with common characteristics and experiences (Smith & Osborn, 2003). Data generation continued smoothly with eleven participants.

1.8.4. Research Methodology

Townsend and De la Rey (2011: 23) state that research methodology offers specification of actions performed in order to answer the research questions. The following section introduces the research methodology followed in the research design.

Qualitative research methods were developed in the social sciences to enable researchers to study social and cultural phenomena; and the research methodology considers and explains the strategy of enquiry, the data generation methods and analysis procedures employed for a study (Welman, Kruger & Mitchell, 2005: 2). Elements which facilitated the empirical investigation include the following:

- **Literature review**

Rubin and Babbie (2008: 120) argue that the literature review is not completed at any point in the research process. They view it as significant not only in the formulation phase of a study, but indeed in the entire process of designing the study. Punch (2005: 71) points out that the literature review should be brief enough to avoid tediousness yet at the same time it should be expansive enough to provide sufficient information on the topic.

The objectives of literature reviews (Bless, Higson-Smith & Sithole, 2013: 49-50) were achieved as follows:

- Studying different theories and views related to the topic of the study deepened and sharpened the researcher's theoretical framework. This serves to establish credibility as it reflects the researcher's knowledge of the area and its major issues, as recommended by Kreuger and Neuman (2006: 241);
- By reviewing ample journal articles, the researcher became acquainted with the most recent opinions and developments in the area of research. Previous results were a starting point for the researcher to widen and deepen existing research efforts (Grinnell & Unrau, 2008: 47);
- Scrutiny of peer reviewed journal articles and other relevant literature provided evidence of relevant shortcomings in previous research for the researcher, and showed the researcher how others have delineated similar problems, as suggested by Monette et al (2008: 81);

- The researcher discovered relations between different research results by comparing various investigations, and also identified variables to consider in this research by comparing different studies done in different contexts (Kreuger & Neuman, 2006: 461);
- The researcher's insight into the research topic was enhanced by reviewing related research. Furthermore, it helped narrow the focus of the research project (Monette et al (2008: 81) and stimulated the identification of thought leaders in the field of study (Grinnell & Unrau, 2008: 47). Case in point evident in the two literature review chapters of this study, the researcher has elected to include older significant references to illustrate historical perspectives and progress in the relevant research field.
- Reviewing related and relevant literature over a broad time span served to illustrate and illuminate opinions underpinning the research questions and assisted in refinement of the research questions (Rubin & Babbie, 2008: 120);
- The researcher was able to select relevant topics and keep the focus of the study by investigating what had already been done in the particular area of research, and thus avoiding unnecessary duplication of what others had already done (Monette et al, 2008: 81);
- Through a thorough review of relevant literature, the researcher was familiarized with the advantages and disadvantages of research methods used by others in order to either improve or adopt them for the current research (Monette et al, 2008: 81).

Neuman (2009: 88-90) describes six kinds of literature reviews: self-study, context, historical, theoretical, methodological and integrative. The following three are applicable to this study. First, the researcher's continuous engagement in *self-study* as a vital component is significant to this study; second, a *context* review places DS in perspective within a family context; and, third, an *integrative* review enables connecting the information and ideas gathered from the various methodological techniques and approaches (Neuman, 2009: 101-104). Through the literature of this study, the researcher endeavours to enlighten the reader to that which is known, and not yet known regarding the outcomes of similar previous studies, as well as pertinent aspects related to fatherhood in general, and more specific, the fatherhood experience of a father of a child with DS.

- **Sampling**

Strydom (2011: 223) differentiates the universe, population and sample of a study as follows: universe refers to all potential participants who possess the attributes of interest to the researcher (parents of children with DS); population sets the boundaries in terms of specific characteristics with which the research problem is concerned, such as persons and events (fathers of children with DS); and, the sample is the subset of the population for inclusion in the study (the actual participants of the study).

The purpose of sampling is to collect rich data, which refers to a diverse and wide range of information (Strydom & Delport, 2011: 391). Non-probability sampling represents a group of sampling techniques that help researchers to select units from a population of interest to specific research. In non-probability sampling, sample selection is based on the subjective judgement of the researcher, rather than random selection, which is the cornerstone of probability sampling techniques (Townsend & De la Rey, 2011: 26). From the available non-probability sampling techniques, for this study purposive sampling was employed, as this method allowed the researcher to purposely seek participants to best inform the study (Creswell, 2007: 125).

Primary inclusion criteria for the participants were: South African married biological fathers of any age, socio-economic background, and ethnicity, cultural or religious groups with a child with DS of any gender or age. Selection of participants included the following considerations: a sample group appropriate to the set objectives (sample size of 11 participants); timeous recruitment of sufficient participants; available participants were drawn from the environment accessible to the researcher's geographical location, being Gauteng; and, the sample group was appropriately adequate and diverse in terms of sampling quality (Check & Schutt, 2012: 100). Guided by the clear criteria for inclusion, the researcher was assured of participants who could provide the most valuable, complex and rich information (Bless et al, 2013: 177). Participant biographical information is presented in Chapter Four.

- **Privacy and confidentiality**

Section 1.10 deals with ethical measures. Privacy and confidentiality forms an integral part of the blueprint of this study. As privacy and confidentiality mostly applies to the researcher's self-presentation and conduct to gain cooperation from everyone involved in

the project (Yates, 2004: 161), the researcher deemed it appropriate to include it as part of the design component of the research.

Morris (2006: 246) states that privacy implies the element of personal privacy while confidentiality indicates handling of information in a confidential manner. Accordingly, all participants were informed of possible limits to this principle and assured of the researcher's commitment to this principle. To this end the researcher treated all communication and written responses as confidential, and all biographic or identifiable information about participants as private.

A telephonic interview with each prospective participant preceded the research process during which the research was clearly explained in terms of research conditions, research procedures to be used, the selection of participants, and the expected contribution of the research itself (Neuman, 2009: 376). Privacy and confidentiality issues were addressed and this was reiterated in the follow-up invitational letter, assent form, as well as the declaration (see Addendum A) which was signed by every participant as prescribed by NMMU Ethical Committee.

The researcher respectfully requested participation and cooperation, clearly specifying both verbally and later in the consent document that participation was voluntary. Participants were informed of their choice to discontinue participation at any time without coercion or penalty. The researcher avoided being demeaning or patronising to participants in any way. Babbie (2007: 65) reminds us that the term "anonymous" does not mean confidential. Participants understood that their written responses were not anonymous as these were submitted to the researcher electronically.

None of the participants requested anonymity, despite the researcher's offer to supply stamped envelopes if an anonymous response was preferred. From the outset, the researcher clarified that names would be redacted and responses numbered as soon as electronically submitted responses were printed. This was also for the purpose of minimizing any personal bias from the researcher. The researcher did not commence with the analysis process until all responses were received. Data gathered throughout the research were kept and filed in a manner that prevented the identification of names or any other identifying details (Trafford & Leshem, 2012: 106).

As suggested by Salkind (2006: 38), plans are in place for a debriefing session to discuss the results of the study. In line with this, Patton (2002: 405) reminds us that being through

a directed and reflective process such as participating in a study which involves introspection and reflection on emotive issues, affects the persons involved. Research on human beings, especially if it explores personal and sensitive issues, necessitates regulations regarding its organization, the relationships with participants and their family members, as well as the role of the researcher. This is addressed further in the section dealing with ethical measures.

Participant identities were not disclosed to the two professionals who assisted in the peer check, as names were redacted and responses numbered beforehand. In accord with the privacy agreement with participants, the researcher omitted any identifiable biographical information from this study. The reasons being that the DS community is a relatively small and fairly private group, that a number of the participants hold professional positions, that the explicit undertaking was that their identities would be protected, and, also in respect of the personal and emotive nature of certain responses. Written permission was obtained from every participant to use their first name and the first name of their child in the dedication section of the thesis. From the outset, the cooperation of participants was negotiated on grounds that their privacy would be respected, and this is scrupulously obeyed throughout this study (Henning, 2007: 43).

- **Data generation**

Briefly defined, data refers to the information which is gathered by the researcher during a research study. Data generation is the root of any research, and based on thorough analysis of the raw data, conclusions are ultimately determined (Townsend & De la Rey, 2011: 27). According to Neuman (2009: 367), qualitative data generation relies on imposed parameters by defining the *setting* (the socially defined territory); the *members* (study participants); *the events* (the study context); and the *case for study* (the evolving nature of events as perceived and experienced within the setting). Several methods can be used for generating qualitative data, the most common being observation, interviews, questionnaires and focus groups. Based on the research questions, the researcher's decision was initially divided between using personal interviews, a focus group interview, or questionnaires for data generation. Either of these methods would suit a qualitative investigation of the chosen research topic. Interviews are usually guided by predetermined open-ended questions; questionnaires are distributed to participants who respond at their leisure; and focus group interviews entail a group discussion that explores the particular research topic (Townsend & De la Rey, 2011: 29).

The advantages of these methods are as follows: interviews allow researcher engagement with the participant, as this can be seen as a conversation with a purpose; questionnaires provide participants privacy, time and space to reflect on their experiences and their responses before writing them down in their own words (Townsend & De la Rey, 2011: 29); and, the focus group interview generally elicits a variety of perspectives as participant responses stimulate and initiate more comments and additional information from other participants, according to Onwuegbuzie, Dickinson, Leech and Zoran (2009: 1).

The researcher considered two critical factors of a focus group interview that could potentially bias and influence the data, as cautioned by Duggleby (2005: 833). Firstly, focus groups tend to become influenced by one or two dominant people in the session, and, secondly, that it may be difficult for some participants to share their real feelings towards some sensitive issues publicly. The latter became evident when all the participants declined the option of participating in a focus group setting or doing a one-on-one interview. Clear preference was shown for the questionnaire self-report method.

The researcher considered the following advantages of the questionnaire method: the format is familiar to most participants; simpler to administer; cost effective; information is collected in a standardised way and as such, analysis is less complicated. However, the three determining considerations for choosing the questionnaire/self-report method were: suitability to the sensitive and personal nature of the issues addressed in this study; affording participants the opportunity to reflect upon the questions and their responses; and most important, that it allows the participants to share their experiences, perceptions and perspectives in their own words, language and narrative (Alcock, Dalton, Graves & Kaur, 2006).

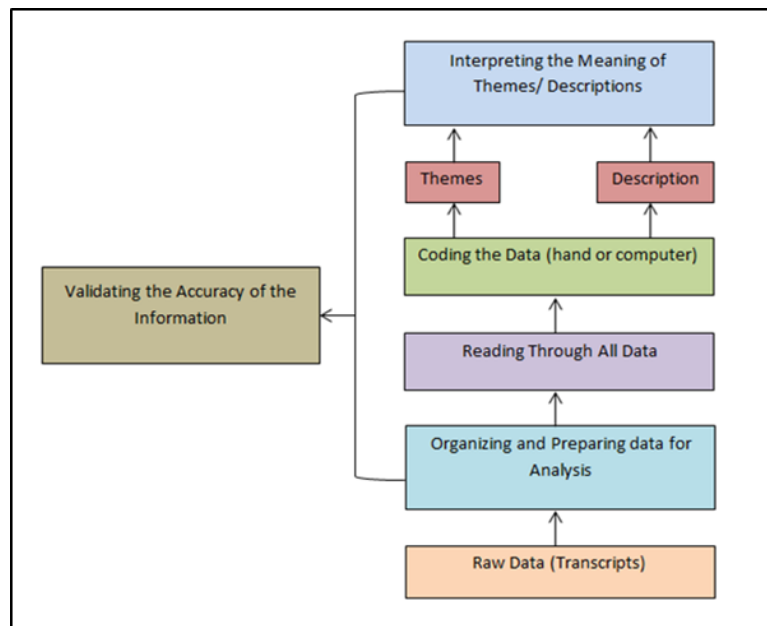
- **Data analysis**

Schwandt (2007: 6) maintains that data analysis is the process by which the researcher brings order, structure and meaning to the mass of data collected, thus this is the activity of making sense of and interpreting data. In the same vein, Babbie (2007: 378) notes that qualitative data analysis is the “non-numerical examination and interpretation of observations for the purpose of discovering underlying meanings and patterns of relationships.” Due to the density and richness of text data in a qualitative study, not all the information is necessarily relevant or can be used, hence Creswell (2014: 195) proposes that the analysis process allows the researcher to hone in on some of the data while disregarding other sections.

Although Holloway and Wheeler (2002: 235) postulate data analysis to be an ambiguous and time-consuming part of research which requires effective time management by the researcher, Schurink, Fouché and De Vos (2011: 398) acknowledge the creative and fascinating components. Conceding that data generated by a qualitative study is voluminous, Schwandt (2007: 7) and later Denzin and Lincoln (2008: xv) remind us that a variety of analytic strategies enable the initial interpretation, sorting, organising and reduction of data into more manageable pieces before it is reassembled.

Although the figure below presents a linear, hierarchical approach to data analysis, building from the bottom to the top, it is suggested that the stages are more interrelated and not necessarily visited in the order presented (Creswell, 2014: 197).

FIGURE 1.2: Data analysis in qualitative research



(Adapted from Creswell, 2014: 197)

The table below offers a useful outline of the differences between qualitative and quantitative analysis. Similarities in quantitative and qualitative analysis are that both forms of data involve reasoning to reach an evidence based conclusion; both are a public method (referring to disclosure of their study design in some way); in both comparison is a central process (the identification of alike and unlike aspects of patterns); and, both endeavour toward accurate and unambiguous conclusions.

TABLE 1.3: The core differences between quantitative and qualitative analysis

Quantitative analysis	Qualitative analysis
Choice of specialized, standard set of data analysis techniques	Less standardised, wide variety of approaches available
Analysis begins once all data has been collected and condensed into numbers	Less distinct as a final stage, allows for subsequent data collections after analysis has started
Numbers are manipulated in order to test hypotheses with variable constructs	New theory and concepts are created by blending empirical evidence and abstract concepts
Language of statistical relationships used in analysis	Words are used that are relatively imprecise, diffuse and context based

(Adapted from Kreuger and Neuman, 2006: 434-435)

According to Kreuger and Neuman (2006: 435), one of the strengths of qualitative methods is “the inductive, naturalistic inquiry strategy of approaching a setting without predetermined hypotheses.” As this study is situated in a phenomenological paradigm, the interpretive phenomenological analysis (IPA), thematic analysis (TA) and content analysis (CA) were primarily considered as possible methods for data analysis. These options are explored in Chapter Four. Based on the conceptual framework of this study, thematic analysis (TA) is in line with both the researcher’s philosophical paradigm and research approach. This involved searching across a data set (including self-reports and a range of texts) to find repeated patterns of meaning (Braun & Clarke, 2006: 77).

- **Distinctiveness of the qualitative report**

According to Delpont and Fouché (2005: 424) the qualitative report is distinctive for the following reasons: it is in essence more complicated than the quantitative report as is it less structured, flexible and open-ended and thus continues to evolve over the course of the project (Leedy & Ormrod, 2005: 143); it is more intertwined with the total research process, meaning that the researcher writes throughout the time of data generation and analysis (Glesne, 2006: 176); and, often it is longer and more descriptive. In this study the researcher uses varied and literary writing styles (Neuman, 2009: 473). The researcher, though favouring the narrative writing style for its personal, familiar and friendly aspects, remained mindful to present the scientific research process followed,

data obtained and the results thereof in a professional and academically rigorous manner (Babbie, 2007: 503).

Although the nature of the qualitative research report is invariably influenced by the nature of the study and the design selected, the following specific criteria identified by Guba and Lincoln (2005), are particularly applicable to a qualitative report. The researcher endeavoured throughout to adhere to the following criteria:

- The report being clearly and self-evidently reflective of the guiding paradigm of the study: *axiomatic criteria*;
- The basis of the report reflecting clarity, simplicity and craftsmanship of the researcher: *rhetorical criteria*;
- The report should be educative and reflect empowerment as part of the report, thus it should evoke action on the part of the reader: *action criteria*;
- The inclusion of detailed descriptions and vicarious experiences whereby the reader can draw inferences relating to their own situation, adds quality to the report: *application or transferability of criteria*.

1.9. ETHICAL MEASURES

The ethical treatment of research participants is the most important and fundamental issue for the researcher (Babbie, 2007: 62). Johnson and Christensen (2008: 101) refer to ethics as the rules and principles that support that which is valued, thus referring to what is deemed morally right and wrong. Throughout this study, the researcher makes every effort to adhere to a personal strict code of conduct specifically with reference to “the fabrication, falsification, or plagiarism in proposing, performing, or reviewing research, or reporting research results” (Johnson & Christensen, 2008: 103). The Belmont Report (1979), which essentially guides this research study, refers to “epistemic imperative” as the moral obligation of the researcher to seek truth and knowledge in what is under research, whilst remaining neutral and functioning in integrity throughout the research.

Prior to commencement of this study, the researcher was granted ethical clearance from the Research Ethics Committee of the Nelson Mandela Metropolitan University. Clearance number: H10-EDU-ERE-015. During both the planning and execution of this qualitative research, the researcher adhered in a morally sound manner to all the protocols of The Belmont Report (1979) in accordance with NMMU ethics.

The objective of The Belmont Report (1979: 1) is to provide an analytical framework to guide the resolution of ethical problems arising from research involving humans, and comprises of three sections: a distinction between research and practice, a discussion of the three basic ethical principles, and remarks about the application of these principles. In terms of the distinction between research and practice, the general rule is that if there is any element of research in an activity, that activity should undergo review for the protection of the participants.

In accordance with The Belmont Report (1979) and as recommended by Creswell (2014: 98), the researcher upholds the basic ethical principles pertaining to honesty, fairness and respect toward participants, beneficence, and justice, with no attempts at misleading or deceit of participants or readers of the study. During the course of this study care is taken by the researcher to conduct all research in a professional, caring manner. This is discussed previously in the section on privacy and confidentiality which confirms how the privacy of participants, and their rights and dignity in relation to personal space, confidentiality, and autonomy are observed and respected throughout the study (Creswell, 2014: 98). As stated before, participation was by invitation and voluntary.

Absolute confidentiality is upheld regarding participants' information and participants remain anonymous to the reader. The researcher suspends any judgement and demonstrates respect for participants at all times (Neuman, 2009: 376) treating the information provided, as well as the manner in which the information is disseminated with equal sensitivity (Cohen et al, 2011: 321). In reporting the research findings, the researcher takes great care to neither embarrass nor be intrusive to the participants. All information and personal interaction is dealt with in a sensitive and respectful manner.

The researcher makes every effort to mindfully observe and respect the tradition and social law such as religion, culture and intellect of every participant. In accordance with social responsibility and as complementary expression of beneficent actions in this case, the researcher acts justly, impartially and respectfully toward everyone involved in the research study with no attempt at misleading either participants or readers, adhering to the Hippocratic maxim "do no harm." As the obligations of beneficence affect individuals and society at large, the researcher gave much forethought to maximize the benefits and reduce any risk that might occur from the research, as cautioned by The Belmont Report (1979: 5). In this regard the researcher conferred with the supervisor at every stage of the study, from the planning stages and throughout the entire process.

The third ethical consideration refers to justice, understood by the researcher as the sense of fairness in distribution of the outcomes of the research study. The benefit of this study has been discussed, but mostly this study is intended to expand the general understanding of the fatherhood experience of South African fathers of a child with DS in order to significantly provide a context for fathers of children with DS who did not participate in this study, and those fathers who are still to come. Stipulated by The Belmont Report (1979: 6), justice not only refers to the equal treatment of every participant to this study, but hence, also to the distribution of the relevant information resting on the outcome.

1.10. RESEARCH OUTLINE

Based on the analogy “Welcome to Holland”, this study consists of six chapters demarcated as follows.

Chapter One: “Ladies and Gentlemen, fasten your seatbelts...”

This study commenced with the introduction and rationale in *Chapter One*. Incorporated in this chapter of this empirical study, is the background and objectives to the research, the problem statement, research questions and research aim, and clarification of concepts. This chapter also includes a brief outline on the research design and methodology.

Chapter Two: “This is your captain speaking...”

The theoretical perspectives in a comprehensive literature study regarding fatherhood in general, the role of fathers, responsibility and the influence fathers have on the development of their child, are presented in Chapter Two.

Chapter Three: “So this is Holland...”

Chapter Three presents a comprehensive theoretical overview of the diagnosis of DS. This chapter elucidates fatherhood pertaining to the diagnosis of a child with DS, as well as the effects on the father and the family in terms of family dynamics and family functioning.

Chapter Four: “We are approaching Holland. Do not disembark without your map firmly in your hand...”

Chapter Four offers an explanation of the research design and methodology of this study.

Chapter Five: “It’s just a different place...”

The findings of the research are analysed and presented in *Chapter Five*.

Chapter Six: “Remember to admire the Rembrandts and tulips...”

The study’s conclusion and recommendations are presented in *Chapter Six*. This chapter also includes a brief outline of the limitations of the study and suggests further research topics, which might be studied in greater depth in future.

1.11. CONCLUSION

Much of the available research viewed within the context of disability still places the father on the periphery of the family. The present research is designed to provide supportive data that delineates the father’s role specifically in his fathering experience and his perceptions and perspectives related to raising his child with DS. The research questions probe the enquiry around this position.

Chapter One places the study into context by providing the background and orientation of the study. The study is positioned on the spectrum of purpose and meaningfulness. Casting the foundation of this study, are the carefully formulated research questions and intended consequent objectives. This chapter further clarifies the researcher’s philosophical foundation and clearly maps out the conceptual framework of this study. Ethical aspects are discussed that relate to the research and the researcher. A research outline concludes this chapter and directs the reader through the journey that this study follows.

This study presents two literature chapters. Chapter Two leads with a presentation of fatherhood in terms of theoretical perspectives, the roles of the father and approaches to fatherhood. The second of the literature chapters, Chapter Three, offers a glimpse into the aetiology of DS and presents historical perspectives, and how shifts in these perspectives relate to fathers of children with DS. Aspects of family and family dynamics within this particular scenario conclude the literature chapters.

CHAPTER TWO

LITERATURE REVIEW ON ASPECTS OF FATHERHOOD

2.1. INTRODUCTION

Research and evidence on fatherhood is far more abundant now than it has ever been; thousands of research papers and articles on the subject have been published over the last quarter of a century. Discourses of new fatherhood call on contemporary fathers to enact the dual roles of financial provider and of engaged caregiver (Marsiglio & Pleck, 2005: 250). In this chapter, the researcher draws on several reviews and seminal works to present a summary of what is known about the meaning of fatherhood, within the boundaries of this study. In doing so, emphasis is on two emergent themes: the roles of the father and factors that may influence his role. In this regard it refers to fatherhood in general as well as his role as father of a differently abled child. Chapter Three will focus specifically on the father of a child with DS.

It would be an ambitious undertaking to include the multitude variables on the spectrum of fatherhood including the vast range of diverse cultural, social and religious practices and socio-economic echelons. In this chapter we look at the following aspects of fatherhood: definition; what it means to become a father; theories, and historic and contemporary perspectives; the roles and child-rearing approach of the father; and, what responsible fatherhood entails. Experts in the field of fatherhood frequently refer to the stalwarts in their research which prompted the researcher to include older literature. This was done to draw attention to development in research, to show progress and/or change where relevant, and because this literature remains relevant at present.

2.2. DEFINITION OF FATHERHOOD

“Fatherhood is increasingly becoming a site of complex structural and personal responsibilities. A combination of the two has arguably always happened in the fathering role, but due to the nature of contemporary social life this phenomenon is increasing” (Williams, 2008: 490).

It appears that fatherhood per se has no singular definition. Rather it is a culmination of a handful of characteristics, behaviours and attitudes which are most closely linked to the essence of responsible fatherhood which will be discussed later in this chapter. According

to Lamb (2010: 3), cultural, historical and familial ideologies will inform the roles fathers play. Furthermore, this may shape the amounts of time fathers spend with their children, it may also influence the activities they share with them, and ultimately, it may impact on the quality of the relationships between fathers and their children (Lamb, 2010: 3).

Coleman (2009: 62) defines fatherhood as the “kinship relation between an offspring and the father.” In contemporary research literature, the term fatherhood is used interchangeably with the term “fathering” which includes, beyond the procreative act itself, all the child rearing roles, activities, duties, and responsibilities that fathers are expected to perform and fulfil (Garfield, Clark-Kauffman & David, 2006: 2365).

2.3. BECOMING A FATHER

“The doctor clipped the umbilical cord and handed me this new little being. He was all wet and wrinkled, and I held him to my chest, wanting to wrap him in my body and arms and keep him warm and safe. So precious. I offered his little hand my finger and he clutched it, each perfect little fingernail staring up at me; each little knuckle formed by minute folds of beautiful pink skin. My world was transformed—later I realized that it wasn’t only my world. I myself became a new person in the process” (Anonymous on becoming a father).

Beginning in early childhood, views about what it means to be a father and the roles of fatherhood are constructed over many years. Boys become fathers to boys who will become fathers in the future (Cabrera, Tamis-LeMonda, Bradley et al, 2000: 127). The researcher was unable to locate any research describing the path that move boys to the practice of fathering or any theory explaining the complex set of developmental processes that give meaning to and shape the practice of fatherhood as suggested by Lamb (1997: 310).

In 1998, Tanfer and Mott (p 250) argued that little was known about how men learn to be fathers. By 2000, Cabrera et al (p 128) confirmed the dearth of research on what shaped the meaning of fatherhood to boys as they move toward adulthood. This included how they viewed role models; the informal assignment of household tasks and responsibilities; the articulation of ideas and values by adults; and, formal instruction. At that time, these researchers acknowledged that the available research did however suggest that the connections between fatherhood and childhood experiences were neither simple nor consistent across individuals. For example, that fathers tended to parent more like their fathers than like their mothers (Losh-Hesselbart, 1987: 536), but that few fathers -

ironically, even those who tended to take less responsibility for their children - said they learned to parent from their own fathers (Hofferth, 1999).

Cabrera et al (2000: 129) noted that fathering involves the repetitive enactment of action patterns in the context of family life that seem connected to generative fathering earlier in life, such as nurturance, distance regulation, problem-solving, stress management, and displays of affection and aggression. In comparison to findings of Hofferth and Cabrera et al, Williams (2008: 494) found evidence to suggest that the view on fatherhood of many men were informed by a strong desire *not* to be like their own father. Findings from his study illustrated that not only are men more aware of 'good' and 'bad' models of fathering (and that they make normative judgements about particular types of behaviour), but that they endeavour to distinguish their own parenting practices from those they judge negatively. Drawing on such distinctions appears to help fathers make sense of their own roles and responsibilities as they engage in self-conscious reflection on what it means to be a father, primarily via comparison with their memories of their own fathers (Williams, 2008: 500).

Although Hofferth (1998) found that fathers with more gender-equitable attitudes tended to be more active, responsible, and warm, and monitored their children's behaviour more than those with less gender-equitable values, Garfield et al (2006: 2365) asserted that previous caretaking experience and non-gender-stereotyped task assignments during childhood increased the likelihood of father involvement during adulthood. In this regard, Witt (1997: 254) argued that the meaning and practices of fatherhood were found to be related to gender identity and to men's experiences with their own fathers and other kin. For example, men whose fathers were involved in raising them were found to be more involved with their own children, to take more responsibility for them, to show more warmth, and to more closely monitor their behaviours and activities (Hofferth, 1999).

Becoming a father influences the father's own development (Cabrera, 2000: 131). Limited literature exists on the transitions in attitudes and behaviours that fathers experience at various points in their children's lives (Snarey, 1993). Fathers play many roles within the family and each of these roles is associated with a set of ideas, competencies, and action patterns. Research on the development of fatherhood is complicated by the fact that there is no singular set of developmental end points or tasks that define competent, supportive fathering for all men (Cabrera et al, 2000: 132). This is particularly true where fathering outside the traditional family model is concerned. In fact, the majority of men assume and enact fathering roles outside of, or in addition to, the traditional circumstance, whether as

step-fathers, non-residential fathers, single fathers or fathers of adult children, even though highly involved co-parenting, responsible fathering, and generative fathering have emerged as idealized, generic goals for male parenting (Doherty et al, 1998: 278).

Traditional and generative models of male parenting did not consider the role that the child's developmental stage plays in the development of fatherhood (Cabrera et al, 2000: 131). Men do not father in a social vacuum; thus the bi-directionality of the father-child relationship needs to be considered in determining the development of fatherhood. As the child grows and develops, displaying a new set of developmental assets (as well as liabilities), it stands to reason that the father is also developing and changing. The importance of father involvement and the contemporary perspectives of the fathering role are discussed in the following section.

In terms of the timing of fatherhood, this is often a determinant of the paths that fathering takes, as well as the management of related developmental tasks. According to Cabrera et al (2000: 132), the timing of fatherhood sets men on different life course trajectories depending on their own developmental stage. Compared to the transition to fatherhood for adult males, the transition to parenthood for adolescent males is more likely either to constitute a "crisis" or to signify little beyond the event itself (Marsiglio, 1998: 245). When young men become fathers, it is often unintentional, whereas for older men, having a child is most often an intended event (Cabrera et al, 2000: 132).

Participating in labour, witnessing birth, and holding his new baby have a profound effect on a father and as the first minutes become a part of a powerful and permanent bond between the two, the groundwork is laid for a man's life-long relationship with his child (Reed, 2001). Bonding is an essential part of the foundation on which all future development builds and researchers have found little difference between the child's attachment to mothers and fathers (Cole & Cole, 2001). Despite the perceived stereotype of the dad who fumbles frantically with the fragile newborn, Reed (2001) noted that new fathers were neither inept nor uninterested in neonatal interaction, but that they were as engaged with their children as mothers, attended to babies' cues and responded appropriately.

According to Reed, fathers understand that this new being is a unique individual. Greenberg and Morris (1994: 522) interviewed new fathers who talked about their emotions. One dad remembered, "There was much more character in the child than I thought there was going to be at that stage in the face. I mean it didn't remind me of

anybody, but it seemed to have a personality immediately.... It was absolutely incredible, the sight itself.” Greenberg and Morris refer to this attraction as ‘engrossment’ as fathers become filled by the image and idea of their new child. Most fathers feel elation at the sight of their new-born and the feeling remains for several days. Fathers who experience birth as a positive event have stronger relationships with their new-born, thus engrossment lays the groundwork for the future relationship between the father and child (Reed, 2001).

2.4. HISTORIC AND CONTEMPORARY FATHERHOOD PERSPECTIVES

“The classic stereotype of Victorian fatherhood is captured within the family photographic portraits of that era. The figure appears authoritarian, impervious and detached; the unbending backbone of the family, imposing structure, but unconcerned with nurture. This image of the father was the nineteenth century legacy. However, in the last century, fatherhood redefined itself. The strict patriarchal model, generated by Victorian Society, faded. By the end of the twentieth century, the acceptable father figure was ‘softer’, more liberal, and one who acknowledged the need to ‘get in touch with his feminine side’” (Carpenter, 2002: 196). Perspectives and patterns of fatherhood have varied throughout history and although it is valuable to track this evolution, the traditional definition of fatherhood is no longer totally helpful to modern families (Carpenter, 2002: 196). Relevant and significant older citations are included in this section to show the progress and development in the field.

- **Historical perspectives**

In the traditional model of fatherhood, fathers played a dominant role in the lives of their children, assuming a broad range of responsibilities defining and supervising the children's development. Domestic control was largely in the hands of men and wives were expected to defer to husbands on matters of childrearing (Carpenter, 2002: 196).

A father's moral role and educational role persisted through childhood into adult life, with the latter centred on reading the scriptures and being instilled with Christian values (Lamb, 1995:19). . His influence was pervasive and usually exceeded the mother's responsibilities over the child until the beginning of the nineteenth century, with the shift away from an agrarian to an industrial mode of production, paternal control over children began to erode (Tanfer, 1997).

The spatial separation of work and home helped revise marital and parental roles. For fathers, this was the beginning of an almost exclusive emphasis on economic responsibilities which led to the disappearance of certain key elements of traditional fatherhood, for example, father as moral overseer, to the transformation of others, such as father as role model (Tanfer, 1997).

During this period characterized by the breadwinning role, men still continued to act as disciplinarians in the family, however, removal from the home weakened their emotional bonds and the father now derived his status from the outside world, from his place in the market place; his occupational standing, his economic power established not only his authority in the home, but his worthiness as a husband and father as well. (Lamb, 2010: 3). With the possible exception of the Depression and war years, when many men were unable to live up to this image, the image of the father as good provider remained intact through the Second World War years, until the men returned from the war (Tanfer, 1997).

During the Depression years, the existent division of labour was abandoned by necessity as women were forced to take up a more active economic role, and men were obliged to share domestic chores. This domestic order remained basically unchallenged until the late 1960s and early 1970s when the confluence of a number of trends fundamentally transformed the family. While economists, sociologists, and demographers continued the debate on cultural versus structural factors of this change, feminist scholars contended that the feminist consciousness reawakened before men were experiencing their own resentments about the burdens of the good provider role. According to Pleck (2007: 35), men were gradually retreating from this role because they felt socially and emotionally imprisoned by the narrowly defined masculine role and there was an increased interest to shed the exclusive responsibilities of providing for their families.

The changes in the family and the decline of the good provider role came about when social structural changes converged with ideological shifts in gender roles (Roy, 2004: 92). Lamb (1995: 20) termed the period that followed as the emergence of the 'sex role model', where the father was seen as necessary for the (re)production of easily definable sex roles. His primary function was now to show young men how the male fitted into family life in a positive fashion. The shift to contemporary perspectives sees what Lamb (2010: 24) identifies as a significant evolution in the fathering role. Now, 'good' fathers are judged on their involvement with children as well as in their performance of the other tasks performed in earlier epochs (Lamb, 2010: 24).

- **Contemporary perspectives**

Ranson (2001: 58) suggested that there was a notable shift in the culture of fatherhood since the early 1980s, which entailed higher expectations for father involvement in the care of especially their young children. Craig (2006: 261) noted that the prevalence of the 'new fathers' toward being more nurturing, developing closer emotional relationships with their children, and sharing the joys and the work of caregiving with mothers, has led researchers to indicate a shift "toward a social ideal of father as co-parent." However, there is a growing body of research that challenges the extent to which the culture of fatherhood itself has changed.

One much-debated question revolves around the apparent disconnect between the culture and conduct of fatherhood. Craig (2006: 262) drew a distinction between the culture of fatherhood (which encompasses a society's values, norms, and beliefs), and the conduct (or actual practices) of fathers. He suggested that the ambivalence about these changes being in culture rather than conduct may have left the general public to conceive fathers as being more involved and nurturing than they truly are. In this regard, Sunderland (2000: 250) argued that the image and role of the fathers were undermined by portraying them as part-time, secondary, less competent parents with fewer parenting responsibilities and greater breadwinning responsibilities than mothers.

In a South African based study, evidence by Viljoen and Steyn (1996), pointed to a shift away from the male-dominant authority pattern to a state of affairs where the husband was still seen as head of the household, but with his wife as equal partner in the decision-making process. The findings of this study (Viljoen & Steyn, 1996), suggested that, although the husband still held the dominant power position in many families, there was evidence of a movement towards a more egalitarian pattern - a marital relationship characterised by companionship. Developing a more egalitarian outlook involves more than just an equal power distribution regarding decision-making in family affairs. It also presupposes a more equal allocation of domestic task responsibilities therefore there was also evidence of a shift in the level of the man's involvement in the rearing and care-taking of his children.

In a subsequent study, Smit (2003: 401) cited the continued rise in the rate of married women entering the labour market - which leads to an increased number of dual-earner families in society - as the biggest contributing factor in the changing role of the South African father. Smit's (2003) findings indicated that most men were no longer the sole or

primary breadwinners in South African families; however, there was not clarity which new patterns of commitment and involvement these men were developing with regard to their family life. Her research did however clarify that the power relationship between the spouses had undergone changes in the past few decades. Increased market participation led wives to experience increased financial independence from their husbands, which increased their decision-making and bargaining power in the marital relationship (Benokraitis, 1996).

Craig (2006: 262) pointed out that although the conduct of fathers had changed somewhat, it was still mothers who bore the vast majority of responsibility for young children. In this regard, Craig (2006: 275) and Silver (2000: 27) drew attention to fathers' time with children appearing to be more dominated by play and leisure, while mothers' time was more dominated by caretaking tasks; furthermore, that fathers' time with children was more likely than mothers' to be in the presence of the other spouse.

In response, Ancell, Bruns and Chitiyo (2016: 1) note that contemporary perspectives have seen a shift in the role of father involvement related to the development of his child, with increased evidence of benefits of active involvement in especially young children's learning and development. Fox et al (2015: 462) comment: "The conceptualization of father involvement has shifted over the past several decades from simplistic dichotomies of presence-absence, to consideration of the amount of time men spend with their children, to recognition of the multidimensional nature of men's relationships with their children." Father involvement will be discussed later under the heading Responsible Fatherhood.

Millar (2006: 1) pointed out how paternal influence on children and their development became a fairly common area of research within the academic community only in the twenty first century, which he ascribed to the advent of increased pro-paternity consciousness. However, as pointed out in the introduction, much of the presented material remains somewhat illusive and perplexing, whilst the often conflicting opinions of social scientists on the issue of the paternal role in child development, generates further confusion. For example, Auerbach and Silverstein (1999: 399) argued that *neither* a mother nor a father's presence is prerequisite, whereas Farrell (2001: 39) stated that *father* presence is essential for holistic well-being of a child's development.

According to studies conducted by the National Institute of Child and Human Development Research, father presence alone is not enough: just because a father is present does not

necessarily mean that it is good for a child. This is evident in the shift over the last couple of decades from father involvement (present or absent) to father sensitivity, with research focusing on the *quality* of time, rather than the *quantity* of time spent with a child (NICHD, 2010: 210).

According to McHale (2007: 154) increased attention to the complexity of family relationships and the patterns of influence within the family system has become a dominant theme in contemporary research. Research results in this regard show that fathers not only influence children by interacting with them, but also affect maternal behaviour, just as mothers influence paternal behaviour and involvement (Lamb, 1997: 309-313) and children influence their parents. In this regard, Davis, Schoppe-Sullivan, Mangelsdorf and Brown (2009: 143-159) found that the temperament of infants influence the quality of parenting, especially those aspects shared between the parents during the first year of the child's life. Similarly, Lundy (2002: 235), and later Eiden, Edwards and Leonard (2007: 1197) confirmed that harmony between parents appear to be a key predictor of father-child relationships.

The landscape of fatherhood research and fathering has shifted over the last few decades to include widespread recognition of the variety of roles fathers play in their families, the relative salience of these roles, and the broader context in which fathering is practiced (such as such as step-fathers, non-resident biological fathers, gay fathers and adoptive fathers, to name but a few). It is understood that perspectives related to socio-economic and diverse cultural dispositions of fathers may differ vastly from the narrow explication offered here. The researcher does not negate these diverse roles and situations in any way; however, exploration thereof is not relevant to this specific study.

As fathers have become more involved, they have made important and unique contributions to their child's social, emotional, behavioural, language, and educational development (Sarkadi, Kristiansson, Oberklaid & Bremberg, 2008: 157; Flouri & Buchanan 2004: 142), which allows the child to be more competitive in the social world (Geary & Flinn, 2001). The tendency of the contemporary father to be more involved also enhanced maternal, child, and family health (Gage & Kirk, 2002: 17), which is especially relevant to differently abled children, who by and large flourish in a nurturing environment. Such an environment is honed by the emergent new trend in involved fathering as presented in the twenty first century.

2.5. FATHERHOOD: CHILDREN WITH DISABILITIES AND DELAYS

In the discussion below, the terms disability, disabled, differently abled and special needs are used interchangeably. As most research on father involvement is done on fathers of typically developing children (Fox et al, 2015: 462), little is understood about father involvement of children with special needs for the following reasons indicated by Dollahite (2004: 111): the overriding focus on mothers in most research; the treatment of fathers as secondary importance by practitioners; and lastly, the emphasis on the stress and coping of fathers rather than on evidence of men's personal growth, diversity in parenting style, and paternal creativity in responding to their differently abled child.

Given the evidence that fathers are increasingly taking on a co-parenting role, a similar shift in role responsibilities might be expected in families of differently abled children. However, Flippin and Crais (2011: 25) believe this not to be the case and point out that mothers continue to be the primary caregivers of their child with special needs. Hastings, Kovshoff, Brown et al (2005) and Pelchat et al (2003) conducted research to establish differences between mothers' and fathers' expression of stress and coping, and found that mothers of a child with special needs generally express higher levels of stress than fathers. Tehee, Honan and Hevey (2009: 39) concluded that high levels of stress in mothers be attributed to the dual role of primary care-giver and full- or part-time breadwinner. Hence, these researchers suggested that increased father involvement could ease the overall workload for mothers and thereby reduce maternal stress.

Although their study of stress and coping among fathers of differently abled children found high levels of paternal stress among fathers (Salovlita, Italinna & Leinonen, 2003), Dollahite (2004: 111) argued that it is possible to overstate the burdens and ignore the benefits that differently abled children bring to their parents. In this regard, the majority of evidence suggests that parents face many challenges unique to the condition of their child, which is why Fenning, Baker, Baker and Crnic (2014: 332) encourage the exploration of the effects of positive involvement of fathers of children with special needs.

A recent quantitative study set out to measure father attachment that tapped a very strong early bond with their differently abled child (Fox et al, 2015). Their intent was to capture strong feelings of disconnectedness, such as ambivalence, fear of future challenges, and a profound sense of loss which traditional measures do not generally tap. Furthermore, they wanted to capture expression of feelings that reflected positive connectedness to the child, such as relief, joy, confidence, commitment, and purpose. The aim of this research

was to investigate the link between empowerment and involvement of fathers of a child with special needs. Significant findings from the research by Fox, et al, indicate:

- That empowerment may enhance the lives of children with special needs by provision of services that foster family functioning;
- Fathering behaviours can be predicted from their interpretation of the fathering roles;
- Financial strain has no independent effect on father involvement. This confirms findings of Roy (2004: 273) that empowerment and strong father role salience can mitigate the negative effects of financial stress on father involvement with children who have special needs;
- Diagnosis severity does not affect father involvement. This contrasts with findings of Goodman and Glenwick (2012: 2062) that fathers experience greater stress levels when their child's condition is more severe. This positive finding is significant for fathers who have a child who is severely disabled, as other analyses with this data set found that diagnosis severity was associated strongly with parental concerns about their child's future. In this regard, Fox and colleagues confirm research conducted by De Falco, Esposito, Venuti and Bornstein (2009: 498) indicating that fathers of children with disabilities may become as involved in child care activities as mothers; and, they may be as deeply connected and emotionally available and sensitive during interactions with their child as mothers.
- Socio-economic indicators were not found to be directly related to father involvement; however they were significantly related to father identity measures.
- No difference was found in the level of father involvement and the gender of the child.
- An interesting finding related to measures of engagement and responsibility indicate that the attachment of father to the child is emotion-based and not behaviour-based. This could indicate that it may be easier for fathers to endorse deeply held feelings of connection rather than interact with the child.

2.6. THEORETICAL PERSPECTIVES RELATED TO FATHERHOOD

For this study several alternative theoretical models are investigated as underlying theories informing fatherhood perspectives. This is not to say that other relevant models are less important or that these are the only, or the best, possible models. Based on the significant finding in the basic research literature that there are stronger associations

between quality of father-child interactions and child outcomes than there are between quantity of fathering and child outcomes (Lucassen, 2011: 987; McDowell & Parke, 2009: 227), the various models below are promising theories that may prove useful for the specific field of the current study. The idea that there is not one best approach to influencing the father-child system is consistent with the researcher's ontological perspective of multiple realities. The researcher concedes that some theories may over time prove partly or totally invalid.

This section begins with an overview of two of three long-standing theories: the father according to Freud, the father according to Parsons, and, Bandura's social learning theory. This will be followed by outlines of significant theories relevant to the current field of study, including a rationale to relate applicability in each case.

2.6.1. The Father according to Freud

The role of the father in psychoanalytic theory refers to Freud only and inclusion in this study is relative to an increased understanding of personality development of both the father and the child.

- **The Oedipus complex**

Most of Freud's theory pertaining to the father centres on the resolution of the Oedipus conflict. The name *Oedipus* derives from Greek myth where Oedipus, a young man, accidentally kills his father and marries his mother. Upon discovering this he pokes his eyes out and becomes blind. Oedipal is the general term for both Oedipus and Electra complexes (McLeod, 2013). According to Cherry (2015), the Oedipus complex refers in essence to the desire for the parent in both male and females, the unconscious desire to possess the opposite-sex parent and at the same time to dispose of the opposite-sex parent.

As the sole source of gratification from birth up to this point, the mother is seen as the initial love object and the boy is subconsciously sexually attracted to his mother, while the father is viewed as the rival for the attention of the mother and is unconsciously perceived as the enemy. However, the boy realises that the father is unlikely to tolerate his affections for his mother and he fears castration as punishment. Freud refers to castration anxiety, a conflict between the boy's fear of being castrated and his love for his mother. Then, upon discovery that girls have no penis, the boy is disturbed by his conclusion that

they are guilty persons who have already been castrated, subconsciously realising that the threat he feels is not an empty one. Freud concludes that when the boy is faced with the danger of castration, he identifies with his father and represses the desire for his mother until that desire becomes deeply unconscious and the conflict ceases to disturb him.

According to Naidoo et al (2011: 123), Freud's theory of the resolution of the Oedipus conflict is much clearer and more consistent for boys than it is for girls. The attraction of a girl to her father and rivalry with her mother is generally known as the Electra complex (terminology of Carl Gustav Jung to the female Oedipus conflict). This conflict needs to be overcome in order for girls to identify with the same gender parent. According to this theory girls have an infantile fixation upon their mothers as sole source of gratification. When the girl discovers that she has no penis like her brother or playmates (theirs being more visible and impressive compared to her inconspicuously small genitalia), she feels cheated and blames her mother for her lack, which is referred to as penis envy. Openly hostile toward the mother, she turns to her father, wishing to displace her mother in his affections and bear a child by him.

According to Freud, in this way the girl identifies with her mother. However, because the fear of loss of love is not as powerful a motivator as the fear of castration, her identification is less complete than the male's, resulting in her Oedipus conflict never being completely resolved. Interestingly Freud postulated that, since she lacks the powerful motivating force of castration fear, a woman's conscience never fully becomes thoroughly developed. Freud believed that a woman's superego (conscience) never becomes as relentless, impersonal and so independent of its emotional origins as a man's. Thus, she develops an imperfect superego and fails to fully resolve the Oedipus complex (McLeod, 2008). According to Freud, women who fixated at this stage are usually flirtatious, seductive and naïve (Naidoo et al, 2011: 123).

Freud's psychoanalytical approach to personality development assumes that the structures of personality are largely unconscious, suggesting that people are mostly unaware of why they behave in particular ways (Jones, 2005: 18). Behaviour is furthermore assumed to be strongly influenced by an ongoing conflict between unconscious motives, instincts, social norms and past experiences (Naidoo et al, 2011: 120). The background on personality and its development is relevant to this study insofar as it determines the behaviour and response of an individual in specific situations. Thus, it is significant to the role of the father, and how he acts out this role. Freud's

psychoanalytic theory on personality development as a whole encompasses his view on the following main principles.

- **Main premises of Freud's theory**

The first principle of Freud's theory (Swartz et al, 2011: 121) introduces us to the life instincts (referring to the need for survival and development and ensuring the reproduction of the species) and death instincts (representative of the destructive force of human nature). The subsequent principle involves the levels of personality. Freud identified three levels of personality which he compared to an iceberg, with the tip of the iceberg representing the conscious, the preconscious lying between the conscious and unconscious, and the largest section proportioned to the unconscious, which is under the surface.

In brief, explanation of the term 'conscious' refers to experiences which one is aware of at any given moment in time, the *preconscious* includes one's memories, thoughts and perceptions that one recalls once brought into the state of consciousness, and the unconscious contains the emotions, instincts and memories that stay hidden in the unconscious mind as they are too threatening to the conscious mind (Swartz et al, 2011: 121).

- **Structure of personality**

Structure of the personality forms a significant principle of Freud's theory, and is described by Naidoo et al (2011: 12) as follows: The *id*, as a forceful component of personality structure, provides energy for the other components, despite being entirely unconscious. Instincts and libido are contained within the *id* and directly relates to bodily needs. It operates according to the pleasure principle and as such has no awareness of reality, seeks immediate gratification and is inconsiderate of the needs of others.

Freud referred to primary-process thought as the manner in which the *id* fulfils its needs, i.e. through wish-fulfilling fantasy experiences of reflex action. According to Naidoo et al (2011: 121), very young children are motivated primarily by the *id*. Once these young children develop mental functions such as recognition, perception, memory and judgement and they learn how to interact with the world, secondary-process thought comes into play. These rational abilities are contained in *ego*, which is the second component of personality.

Naidoo et al (2011: 122) offer the following description of ego in this paragraph. The *ego* is reason driven and relieves the tension between the id and reality, thus allowing the id's impulses to be satisfied at the right time, right place, by using acceptable objects and in socially appropriate ways. Because the ego guides behaviour by reason, it is said to follow the reality principle. Simplified, the ego can divert anger from aggressive behaviour into a socially acceptable activity such as, for example, exercise.

The ego does not attempt to prevent satisfaction of the id, but it does control the expression of the id's needs. The personality's internal moral code is known as the *superego* and contains the notions of right and wrong learned during childhood from significant others, and includes acceptable behaviours and responses, which leads to development of the conscience, an element of the superego.

Naidoo et al (2011: 123) explain further: Internalisation transpires once what is good and what is bad has been consolidated unconsciously and the rules of right and wrong become self-administered and self-control rather than parental control is in place. The superego develops during early childhood (when the child identifies with the same sex parent) and is responsible for ensuring moral standards are followed. As the superego is insistent on moral behaviour, behaviours contrary to our conscience result in guilt and shame. Hence the superego, unlike the ego, can obliterate certain id drives such as aggression and sex.

The ego serves as a go-between to satisfy the forces of the id, the superego and reality and when the ego can no longer cope with these demands, inner conflict and anxiety develops (Naidoo et al, 2011: 122; McLeod, 2008). The ego can deploy various defence mechanisms, amongst these are denial, sublimation, intellectualization, compensation, and reaction formation. And although they vary in detail, each is employed to reduce the conscious tension that would otherwise be experienced by the ego to prevent it from becoming overwhelmed by anxiety, as indicated in the table below (Freud, 1964).

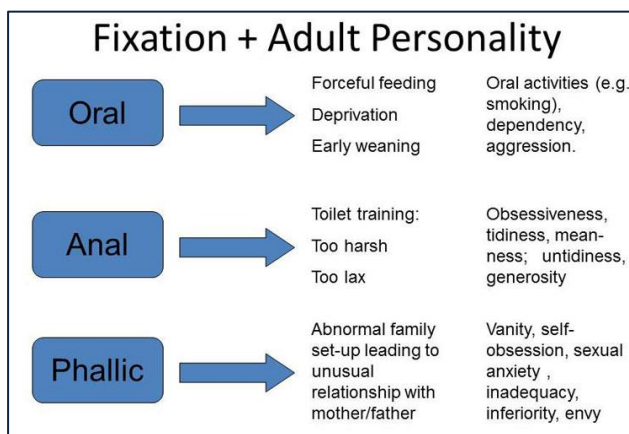
FIGURE 2.1: Defence mechanisms deployed by 'ego' state

Mechanism	Description	Example
Repression	Repression is an unconscious mechanism employed by the ego to keep disturbing or threatening thoughts from becoming conscious.	During the Oedipus complex aggressive thoughts about the same sex parents are repressed
Denial	Denial involves blocking external events from awareness. If some situation is just too much to handle, the person just refuses to experience it.	For example, smokers may refuse to admit to themselves that smoking is bad for their health.
Projection	This involves individuals attributing their own unacceptable thoughts, feeling and motives to another person.	You might hate someone, but your superego tells you that such hatred is unacceptable. You can 'solve' the problem by believing that they hate you.
Displacement	Satisfying an impulse (e.g. aggression) with a substitute object.	Someone who is frustrated by his or her boss at work may go home and kick the dog,
Regression	This is a movement back in psychological time when one is faced with stress.	A child may begin to suck their thumb again or wet the bed when they need to spend some time in the hospital.
Sublimation	Satisfying an impulse (e.g. aggression) with a substitute object. In a socially acceptable way.	Sport is an example of putting our emotions (e.g. aggression) into something constructive.

(Adapted from Freud, 1964)

This led to the most controversial part of Freud's work, his theory of psychosexual development and of the Oedipus complex. Freud believed that children are born with a libido – a sexual (pleasure) urge, and during different stages of childhood, the child seeks pleasure from a different object (Naidoo et al, 2011: 122). In order to obtain psychological health, each stage must successfully complete. Naidoo et al (2011: 123) caution that mental abnormality can occur if each stage is not completed successfully and the person becomes 'fixated' in a particular stage. Relevant to this research, this particular theory shows how adult personality is determined by childhood experiences (both retrospectively for the father, and with a future view for the child).

FIGURE 2.2: Fixation, cause and effect on adult personality



(Adapted from Naidoo et al, 2011: 122-123)

- **Freud's inference**

Developmental psychologist, Lynn, is one of the first modern day researchers who, in the 1970's made significant theoretical and research contributions to our understanding of the father's role in the child's development. At that time, most of the well-known studies of socialization concentrated on various types of mother-child interactions of family milieus which investigated the consequences for the child development of children's personality and social behaviour, while very few studies included father-child relationships and their outcomes (Jones, 2005: 8).

Freud believed that children feel safe under a father's protection. Despite being stronger as adults, the perils of life are often overwhelming and we remain fundamentally as helpless and unprotected as children, reinforcing a yearning for a protective father (Jones, 2005: 9). Jones further postulated that on a spiritual level, this notion sustains our belief in a Higher Power and the perpetual search for strong leaders, mentors and guides. Freud was convinced that the father was responsible for the development of principles, rules and values of society within a child, and if the father was missing, this negatively affected the child's view of his position in society (Williams, 2008: 48). Freud thought the father represents the authority of society instilled in a child, which runs parallel with the concept of the superego, and its development (Naidoo et al, 2011: 123).

Elaborating on the theme of the father as society's representative within the family and the family's representative within society, was Talcott Parsons, a sociologist who aligned himself with the structural functional perspective, and according to Haidt (2008: 71), believed that supportive families are the key to successful socialization.

2.6.2. The Father according to Parsons

According to Parsons' theory, the role of the father centred on the structure of the family echoing the structure of society (Millar, 2006). Parsons saw the function of the family as twofold: primary socialization of the children and stabilization of adult personalities. Stabilization of adult personalities refers to the emotional security found within marital relationships which balance out the stresses of everyday life faced by adults (Millar, 2006). Parsons inferred that, although primary socialization occurs during the early years when the child's personality is moulded (immersing society's core values), the stabilization of adult personalities was facilitated by the gender division of labour within the family as an isolated nuclear unit. According to Parsons, for this unit to function correctly, family

members must be allocated particular roles according to their sex/gender (Thompson, 2008).

Parsons postulated that such identification of two distinct roles for the husband and wife within the family not only stabilized family members, but also allowed the family to function. According to Parsons's theory, the father not only brings the society into the family, but brings the family into society. He also brings discipline into a family so that child will accept responsibility and eventually separate from its mother, becoming a part of society and then starting the sequence all over again when the child then becomes a parent (Millar, 2006).

According to Thompson (2008), Parsons argued "that families act like factories with the processes and systems available to it to continually reproduce human personalities in a warm secure environment." Parsons viewed an additional function of the family to allow adults to 'act out' the childlike dimension of their personality. Related to parenting, on a practical level, this is facilitated when parents play with their children using their toys and engaging in playful activities.

Parsons advanced that any group must become one of two functions: expressive or instrumental. As the father fulfilled the instrumental role (primarily but not entirely), Parsons believed that the mother's concentration on child care enabled her to perform the expressive functions (primarily but not entirely), such as dealing with the internal affairs of the family, coping with its stresses and strains, regulating tensions, mediating between family members and providing emotional support in order to perpetuate harmony within the family (Millar, 2006).

Related to this aspect of Parson's theory, Lederer (1998) wrote about the qualifying battle between fathers and sons, making several observations relevant to the instrumental-expressive dichotomy. He maintained that mothers and fathers have two different modes of loving. Mothers love their children simply because they exist; she loves unconditionally. Father's love is demanding and dependent on performance, for what he can do. This conditional love represented the father's instrumental function (decreasing the children's dependency on the mother, compelling them to function competently within society) (Millar, 2006).

The distinctive roles of the mother and the father are clear in the theories of both Freud and Parsons. Maccoby (2003: 399) documented that the gender differences of these roles

were mostly within a social context, assuming here that the father-dyad is different from the mother-child dyad, and the issue being the social interaction with these dyads. According to Parsons' theory, children see the father as authoritative and powerful hence the setting of clear boundaries would be associated more with the father. Farrell (2001: 138) noted that fathers tend to set clearer boundaries, which teaches the child, in turn, to respect the boundaries of others. In this regard, Ang (2006: 246) cautioned that lack of boundaries support aggressive behaviour, highlighting a significant correlation between aggression in boys and poor father-son relationships. The concept of a stable and sound father-child relationship ties up with the Parsons theory as relevant to the child's socio-emotional development.

The onset of industrialization caused a break-up in the kinship-based society, and the classic extended family was replaced by the 'isolated nuclear family' as a 'productive unit'. Parsons identified the families in modern industrial society as being isolated nuclear families. According to Thompson (2008), Parsons' functionalist view of the family has been criticized as having too an idealistic view of the family, for ignoring diversity, and for failing to acknowledge that children also create their own personalities. His views assume that the family works in isolation, often ignoring the role of other institutions in allowing primary socialization to occur in the first place. However, we need to consider in Parsons' time the nuclear family was seen as the ideal type of family, devoid of the diversity of family structures we encounter in modern society.

2.6.3. Bandura's Social-Learning Theory

Albert Bandura, distinguished for his work in social learning, offered the theory of self-efficacy. Naidoo et al (2011: 133) describe self-efficacy as "the beliefs a person has about their ability to carry out the behaviours needed to reach their desired outcomes." According to Howard-Payne and Payne (2011: 231), Bandura based his social learning theory on the concept that "learning occurs when one's behaviour changes after viewing the behaviour of a model." Bandura (1993: 146) added social behaviour to the stimulus-response concepts of Pavlov and Skinner, arguing that people are able to learn new behaviours and information by observing other people.

Known as vicarious learning, this refers to learning that occurs indirectly through the actions of others, and today even includes the media (Howard-Payne & Payne, 2011: 231). The social-learning theory relates to Freud's castration principle, bringing rise to the concept of defensive identification, which includes fear of punishment. Similarly, the

father in Parsons' theory could himself be a role model for vicarious learning. Both the aforementioned theories required shift in the identification of boys from mother to father, especially in the establishing of masculinity, which can be inferred to be facilitated by vicarious learning (observing father).

Applicability of the social-learning theory relates also to the adjustment of fathers of children with disability in order to reach a place of acceptance of both the diagnosis of their child, as well as the inevitable changes of their fathering landscape. Individual adjustment refers to time, duties, roles and coping required by the father to gain firmer footing within his new set of circumstances, as well as adjustment to accepting an unexpected diagnosis; social adjustment; relationship adjustment between husband and wife; and, adjustment to new economic circumstances which may include provision for extra expenses such as therapies and so forth. It can further be inferred that the social learning theory may apply to fathers of children with disability by observing the behaviour of other fathers in similar situations and also learning from them.

2.6.4. Attachment Theory

Attachment theory is associated with secure attachments in father-child interactional quality, and positive father child relationships (Barr, Morin, Brito, Richeda, Rodriguez, & Shauffer, 2013: 11) ultimately to improve developmental outcomes for both the child and the father, and therefore provides a useful perspective for fatherhood research. An important tenet of attachment theory is that parents who are emotionally available and responsive to their children are more likely to have children who are securely attached to their parents. Attachment theory emphasizes the father's sense of closeness to the child and his sensitivity to children's emotional development. Children's secure attachment to the caregiver (whether it is the mother or the father), is considered by researchers to be a hallmark of socio-emotional growth and development in young children (Ainsworth, Bell & Strayton, 1974: 100). These researchers further noted that attachment theory also suggests that the thoughts and feelings that fathers (and mothers) have toward their children are linked to the quality of parenting. Fathers who have positive feelings about their child are likely to be more responsive and sensitive to their infants than fathers who do not have positive feelings toward the child (Grossmann, Grossmann & Fremmer-Bombik, 2002: 207).

According to Fagan and Kaufman (2013:11), the quality of the father's emotional attachment to the child is rated as being very important by more practitioners than any

other indicator of fathering, which justifies attachment theory as an important theoretical framework for fatherhood studies. Zhang (2013: 85) argues that fathers tend to overestimate the quality and quantity of their parenting behaviour. Although measures for assessing quantity or amount of father involvement often utilize self-reported data from either the mother or father, the Relationship with the Child questionnaire (Coley & Morris, 2002: 995) is also a promising measure for assessing quantity of father involvement related to these three aspects of father involvement: responsibility, accessibility, and engagement. Studies have shown strong predictive validity and internal reliability for the Relationship with the Child questionnaire (Hernandez & Coley, 2007: 70).

2.6.5. Family Systems Theory

Fagan and Kaufman (2013: 6) suggested that family systems theory is an important foundation for conceptualizing outcomes and measurement tools in the responsible fatherhood field. Family systems theory suggests that families consist of interdependent components (Fagan & Kaufman, 2013: 6). Specifically, the family is comprised of subsystems that exert influence on one another. This understanding necessitates considerations of the father-child, mother-child, father-mother, and mother-father-child subsystems as they exert direct and indirect influence on one another. Interdependence among subsystems suggests that the mother-father and father-child subsystems have reciprocal influences upon each other. Another important precept of family systems theory is that family functioning is influenced by the broader societal context in which families reside. In the case of fathers of a differently abled child, the broader community (including health care professionals and educational institutions) exert significant influence on the various subsystems of the family.

Referring to the family systems risk-protection-outcome model (Cowan, Cowan & Pruett, 2009: 665), this theoretical perspective assumes there are multiple systemic factors that shape fathers' engagement with their children. Cowan et al suggested that father engagement is associated with risk and protective factors in five areas of family life, namely: individual members' emotional health; inter-generationally transmitted patterns of couple and parent-child relationships; quality of relationships between parents; the quality of mother-child and father-child relationships; and, the balance between life stressors and social supports outside the immediate family.

2.6.6. Social Identity Theory

According to Reicher, Spears and Haslam (2010: 48) social identity theory is linked to fatherhood by its concern with the processes which surround the way the father defines himself as member of a social group, which refers here, is the meaning of the term 'social identity'. At a conceptual level, this theory serves to transform the understanding of identity in psychology. It stresses the sociality of the construct in at least three ways. First, social identity is a relational term, defining who we are as a function of our similarities and differences with others. Second, social identity is shared with others and provides a basis for shared social action. Third, the meanings associated with any social identity are products of our collective history and present. Social identity is therefore something that links us to the social world, and as such, it provides the pivot between the individual and society.

Initiated in the early 1970's by the work of Henri Tajfel, identity theory as a subset of symbolic interaction theory, points to three social psychological factors that are important in the enactment of a social role such as the father role (Fox et al, 2015: 463). These are: a high degree of salience of the role to a person's self-identity; the perception that others in his social environment appraise him favourably in that role; and, a high level of satisfaction in the role (Stryker & Serpe, 1994: 17).

Research results for father role salience have been mixed, but the majority of studies indicate that men who place importance on their fathering role or view their father status as central to their identity are more actively involved with their children than men who place less importance on the role of the father (Pasley, Petren & Fish, 2014: 299). Because circumstances or constraints in other areas of their lives, such as inflexible work schedules or non-residence with the child, may prevent men from enacting their father role preferences, it can be misleading to rely solely on observational or time-based measures of father behaviours as indicators of the salience of the father role, and for this reason self-report measures of role salience are often used (Roy, 2004: 260).

Several researchers have suggested that men's paternal identity is influenced by reflected appraisals; that is, by others' perceptions of his fathering abilities. McBride, Brown and Bost (2005: 265) found that wives' opinions of their husbands' parenting abilities have been especially important in accounting for men's father involvement. Furthermore, role satisfaction is theoretically important to role enactment, and confirmation of this has been found in father involvement research conducted by Fox and Bruce (2001: 395). None of

the aforementioned studies cited included samples of fathers of children with delays and disabilities.

2.7. ATTACHMENT

Evident up to now, it appears that a healthy attachment to his child is a significant component of a healthy fathering experience. This section looks at how attachment influences the child and the father.

- **Benefits of attachment for the child**

According to Miller and Lamport (2010: 1), the first benefit of attachment parenting is that it helps children become physiologically and psychologically healthy. Parents of infants and young children face many challenges when dealing with negative emotions such as crying, distress, fear and anger. If children experience such emotions chronically, and these are not mitigated by parents, evidence suggests that the stress can result in irreversible brain damage. These changes can increase the likelihood of serious problems in children's development (Miller & Lamport, 2010: 5).

Secure attachment patterns in children are very good predictors of child behaviour (Coley & Medeiros, 2007: 144; Pleck & Masciadrelli, 2004: 224). Children who have a secure attachment to their father tend to have improved developmental outcomes in a variety of ways including improved social abilities with their peers, displaying fewer problem behaviours, and development of increased levels of emotional self-regulation (Grossman et al, 2008; Lieberman, Doyle & Markiewicz, 1999: 204). In addition, a secure father-child attachment relationship compensates for potentially harmful effects resulting from an insecure mother-child attachment (Verschueren & Marcoen, 1999: 185). Conversely paternal absence, which invariably influences father-child attachment, has various negative effects on especially boys, such as levels of school achievement, heightened risk-taking behaviours, and higher levels of aggression in boys (Coley & Medeiros, 2007: 145).

- **Benefits of attachment for the father**

A father's own level of attachment security with his parents may influence his own child's attachment security to corresponding levels (Howard, 2010: 155). A father who has a secure attachment style in adult relationships tends to experience lower levels of

parenting stress, lower levels of abuse potential, and a greater amount of knowledge about child development (Howard, 2010: 159). Wong, Mangelsdorf, Brown, Neff and Schoppe-Sullivan (2009: 835) observed that fathers who spend more time with their infants tend to have more positive interactions with them which help foster the attachment security, whilst fathers who work longer hours are less likely to have securely attached infants.

One of the unique properties of father-child attachment relates to the 'playmate' rather than 'caregiver' role that fathers fill. Various studies underpin that fathers are more likely than mothers to encourage risk-taking and exploration in their children by engaging their young children in physical play and initiating games that are both unpredictable and enjoyable (Grossmann, Grossmann, Kindler & Zimmerman, 2008: 892; Cabrera, Fitzgerald, Bradley & Roggman, 2007: 185-189). It has also been suggested that fathers, compared with mothers, are less able to detect low levels of infant distress which may contribute to the mother's greater tendency to fulfil more of a "caregiving" role for the child (Grossman et al, 2008: 895). In this regard, most infants tend to prefer contact with their mothers when they are distressed and seeking comfort, and contact with their fathers when they are in more positive emotional states and seeking play.

However, Cabrera et al (2007: 186) argue that in the role as caregivers for their child, when the mother is working, the father is very capable in fulfilling all of the responsibilities that traditionally belong to the mother, creating a secure base for his child. Marital intimacy and supportive co-parenting is linked to a more secure father-infant attachment relationship and deteriorating marital intimacy is linked to negative father-child interaction (Brown, Schoppe-Sullivan, Mangelsdorf & Neff, 2010: 134).

2.8. THE ROLES OF THE CONTEMPORARY FATHER

Research on parents and children has identified various ways that fathers think about children's development and their own role as parent, their customs or practices of care, and how they organize their children's environments of daily life (Harkness & Super, 2009). Even though any of the following roles can, and often are, capably fulfilled by the mother, literature confirms the following as the roles that fathers define themselves in, and distinguish these as significant for raising their child. Fogarty and Evans (2009) note that wherever their efforts of parenting responsibilities apply, contemporary fathers' roles tend to be defined by the following Five P's: Participator/Problem-solver; Playmate; Principled guide; Provider, and Preparer.

- **Participator / problem solver**

Evidence so far clearly indicates that being there for his child constitutes and requires more than physical presence from a father. The previous section showed how father participation in his child's life supports the child in every domain of development (Fogarty & Evans, 2009).

According to Fogarty and Evans (2008), in the role as problem-solver, the father models effective problem-solving skills for his child. Showing and guiding the child how to make and act on decisions, as well as experience consequences of actions and decisions fosters a child's independence, self-reliance and responsibility. Related to practical examples, helping the child solve many of the critical problems of growing up such as planning and executing a school or hobby project successfully, fixing or constructing things, buying vs. saving, are seemingly simple challenges in which the child is carefully guided for the challenges of emerging adulthood. Gilbert (2010: 249) suggests that modelling problem solving as an integral part of the father's parenting style can take place in structured or planned activities or less obviously in any spontaneous interaction between father and child which stimulates thinking and reasoning and hence the father facilitates the child's construction of new knowledge according to Gilbert (2010: 249).

If a father neglects this critical role of setting an example for problem-solving or applies it too late, the child may develop emotional and behaviour problems. Fogarty and Evans (2009) postulate that children who are raised without a role model for effective problem-solving may adopt ineffective strategies, resulting in helplessness and incompetence in problematic situations. According to Ntshangase (2011: 78), children with deficient problem-solving skills may develop into adults who are needy and dependent. Thus, the social messages that the child receives as he interacts with role models in his environment play an important role in developing his self-concept.

- **Playmate**

Although the father's role of primarily play partner (after provider) has often stereotypically been misrepresented, quality rather than time-based prominent father-child interaction and paternal playfulness has helped make fathers especially relevant to their children's development (Lamb, 2010: 3; Louw, van Ede & Louw, 2008: 221). It is generally accepted that fathers engage playfully with their children. Typically once a father sits down on the ground his children start climbing on and all over him, often resulting in a rough-and-

tumble of note (Paquette, 2004: 194). Rough, physical and stimulating interaction more characteristic of fathers - provided they are warm and responsive - is important as a highly arousing environment in which children build self-regulatory skills, particularly with respect to social competence and nonaggression (Flanders, Leo, Paquette et al, 2009: 286).

Grossmann et al (2008: 892) found that fathers spend proportionally more time than mothers engaged in high-energy, physical activities with their children, incorporating adventurous and stimulating play, which include elements of surprise and excitement. This tends to set up expectation in children for the majority of their interaction with their father involving physical play.

Play is so important to optimal child development that it has been recognized by the United Nations High Commission for Human Rights as a right of every child (2009). Also termed as 'a window to the child's world', play is the way children explore and orient themselves to the world, thus play allows children to use their creativity whilst developing their dexterity, imagination and physical, cognitive, and emotional strength (Vijay Sagar, 2011: 7). Viewed within this perspective, this role of the father must be nurtured, explored and maximized.

Ntshangase (2011: 76) supports this role of the father to encourage the child's sense of autonomy and independence - a major milestone in social and emotional development. The father can achieve this by teaching guiding and modelling not only, but also rules that govern behaviour, for example taking turns, playing physically without hurting someone, waiting in line, solving problems, resolving conflict and planning strategies. A further benefit is that engaged play with his child initiates informal conversation which may provide the father insight into his child's feelings, hopes, thoughts, fears and dreams. Such an informal platform builds valuable emotional bonds, paving the way for more serious conversations. Fogarty and Evans (2009) caution fathers not to miss this valuable opportunity by simply playing and substituting physical contact for purely verbal interaction.

- **Principled guide**

Related to the father role, there is a subtle difference between punisher and principled guide. Ntshangase (2011: 77) suggests that punishment tends to be a negative assertion of adult power, and emphasizes what the child should *not* do, rather than *how* the adult would prefer him to act. If punishment is the result of the adult's emotional reaction to the

child's behaviour, the child may feel humiliated and ashamed, undermining trust in the parent-child relationship. On the other hand, if the behaviour deemed unacceptable was well-meant by the child, undue punishment may undermine the child's initiative and sense of autonomy (Fogarty & Evans, 2009: 2).

Palkovitz (2002: 122) asserts that principled guidance is based on the norm and value set the father lives by and models his own behaviour on; that guidance teaches socially desirable behaviour; provides the opportunity to differentiate between right and wrong; and, enables the child to experience and understand the consequences of his own behaviour. Guidance is therefore a collaborative effort between father and child, an ongoing process of father-child interaction. It is important that both parents agree on guidance strategies, especially when it comes to learning consequences of unacceptable behaviour. Both the child's development and the parental relationship is compromised if one parent reinforces behaviour, while the other parent rescues the child from the experience or consequences of his own poor decisions (Palkovitz, 2002: 123).

Fortunately clichéd threats like "Wait till your father gets home!" no longer has much value, mostly due to the diversity of contemporary family types, but certainly due to the new understanding of child discipline as guidance rather than punishment. Fogarty and Evans (2009) are of the opinion that the father, as principled guide, sustains the delicate balance between correcting unacceptable behaviours and encouraging acceptable behaviour with praise and appropriate reward.

- **Provider**

Although the last few decades have seen mothers entering the work force in unprecedented numbers, fathers continue to be identified primarily as breadwinners of their family (Wall & Arnold, 2007). Apart from the breadwinner perspective, the provision role of the father within the family can also be defined in terms of responsibility for the child. It is not uncommon for fathers who work from a home base to take on much of the care-giving responsibility of their children. Even if they are not directly responsible for providing the care, they may be directly involved in the arrangements and logistics (Fogarty & Evans, 2009).

This role also includes an empowering component, as fathers who identify themselves more as caretakers are more likely to connect with their child and with other parents and

role players in their child's life, which favourably positions them as potentially powerful advocates of their own children as well as for child welfare in general.

Regrettably historical perspectives still linger and many fathers believe that provision of income and material support was their only way for caring for their family (Fogarty & Evans, 2009). Such a mind-set may discourage some fathers from participating in many of the meaningful, fulfilling parenting activities, whilst on the other hand it may potentially become a rather convenient excuse not to get too involved in the parenting of his children (Doucet, 2006).

Biddulph (2004: 21, 22) links the providing-a-role-model role of fathers to their own upbringing and how these unique experiences now influence their current understanding of fatherhood. Referring to the historical perspectives and experiences of fatherhood, it can be accepted that many contemporary fathers are products of their own upbringing in a generation where expected role models such as grandfathers, uncles and fathers were mostly perceived as distant and often detached from their children.

The post-industrialisation generations called for men to provide and for women to raise children, leaving many fathers (now grandfathers) in living memory to appear "gruff, awkward and emotionally shut down" (Biddulph, 2004: 22). Hence, the perpetuation of the notion that 'mother knows best'; a notion that may leave even contemporary involved fathers who make brave efforts to be part of their children's lives, feeling incompetent or lacking in some innate wisdom.

Biddulph (2004: 22) maintains that a lack of mentorship from the obvious available male community (such as teachers, uncles, neighbours, grandfathers) leave boys to misguidedly base their idea of self on a thinly drawn image gleaned from the media and their peers. With a limited sense of self, many boys may live their life based on this one-dimensional façade. Biddulph (2004: 22) contextualizes this further, by suggesting that the friendship network of boys often lack in intimacy, are more likely to be awkward and oblique, and are often more short-term as opposed to those of girls.

Whilst this may not be true for everyone, a lack of in-depth elder male connections during childhood may leave many men bereft and struggling, battling to connect to their own role as father. In contrast, it can be assumed then that the father whose boyhood experiences included exposure to competent, caring men who had been there for him, guiding, encouraging and teaching him through boyhood, teens and the trials of being a young

parent, may subsequently experience fatherhood completely differently from the many fathers who did not have the same privilege.

Biddulph (2004: 22) compares the aforementioned scenario to girls, many of whom may enjoy continuous exposure to diversity of competent and communicative women at home, at school and in their social networks. Such interaction facilitates an open and sharing style of womanhood, and forms a base of communication that invites closeness to give and receive support throughout their lives (Dabrowska & Pisula, 2010: 268).

- **Preparer**

Fogarty and Evans (2009) propose that fathers view themselves through the lens of protector/preparer, preparing their children for life's challenges, and protecting them as they journey toward adulthood and beyond. The role of preparer requires fathers to talk with their children about moral issues, family values, or teenage advice about educational and employment goals, and, when asked, also about peer and romantic relationships. Guidance may further extend to issues of acceptable social behaviour, personal ethics and issues around work ethic as recommended by Palkovitz (2002: 123). Recognising the importance of such behaviour even then, Jain, Belsky and Crnic (1996: 441) pointed out two decades ago that mutual respect and affection between mother and father is arguably the most influential way a father can prepare his child for his own future relationships.

Although a father fulfils the role of protector/preparer throughout the life of a child, it is often only once the child grows into adolescence and adulthood that this relationship consolidates (Fogarty & Evans, 2009). Providing his child with continued moral guidance and using spontaneous events to teach valuable life lessons strengthen the father-child relationship. In this regard Marsiglio, Amato, Day and Lamb (2000: 1189) noted that constant involvement shapes an unending partnership of trust between father and child, and may purposefully inform many areas of his child's life to prepare him to eventually be a father too. While some studies found that fathers strongly influence the parenting style of their children (Nicholson, Howard & Borkowski, 2008: 40), other studies show that men who grew up with fathers who were poor role models, compensated for this by being particularly involved in the lives of their own children (Pleck & Masciadrelli, 2004).

According to Mayekiso (2011: 64), an important aspect of child-rearing is the father's transmission of cultural beliefs and traditions to provide the child with a sense of identity

and a better understanding of the world around him. Unique to South Africa is the word Ubuntu which refers to teaching a child the value of compassion. However, compassion can only be demonstrated by one's own compassionate actions. The concept and understanding of Ubuntu can be located in each of the five P roles as follows: Participator/problem-solver (father participating and problem-solving by means of empathy and practical action), Principled guide (father making a moral commitment to display of compassion as situation requires), Provider (practical application helping or providing as situation requires), and Preparer (adding deed to word through his act, the father prepares the child to do same through his demonstration of compassion in action).

Despite the simplicity of the 'Five P's' approach, fathers who are generally involved in their child's life will find that their role overlaps and incorporates all five categories. It is expected that the role of fatherhood is integrated with the characteristics of the individual who aspires to *be* better and *do* better than his father was, evolving in his chosen role as father. Whilst not definitive as the only roles, the five P's provide adequate guidance for fathers of both typically developing and differently abled children.

2.9. CHILD-REARING APPROACH OF THE FATHER

The previous sections indicate that a supportive, secure and loving environment which provides guidance, love and care is a positive marker for the development of a stable, well-adjusted sociable human being.

Parenting styles can be thought of as the general atmosphere in which parent-child interactions take place and a multitude of parenting styles exist (Kreuger, 2015). Researchers at the University of Virginia's Institute for Advanced Studies in Culture recently established four new styles, namely: faithful parenting (based on religious morality of parents); engaged-progressive (based on either parents' own personal experience or what 'feels right' to them personally); detached parenting (in line with laissez-faire parenting); and, the American-dream style parenting (characterised by optimism about their children's opportunities and schooling; they hope for much and invest even more in their child, and pour themselves fully into their families' futures).

This is one of the many new developments since psychologist Diana Baumrind's (1967) scientific approach to parenting styles in the 1960's characterised parenting as either 'too hard', 'too soft' or 'just right'. The latter includes authoritarian parenting, authoritative parenting and permissive parenting (Mayesiko, 2011: 65). Positive parenting leader,

Coste (2010), refers to contemporary powerful parenting styles based on parents' high-level philosophies and insight into love: positive parenting, attachment parenting, unconditional parenting, spiritual parenting and slow parenting.

Although no empirical evidence exist to support these specific parenting approaches, it appears to be largely informed by mindfulness-based strategies, which MacDonald and Hastings (2010b: 514) support as effective in any parenting style or strategy. In this regard, findings by Baer, Smith and Hopkins (2006: 28) and MacDonald and Hastings (2010a: 513) confirmed that mindfulness-based parenting outcomes include reduction in psychological distress and improved parenting interactions and behaviours.

Literature addressing children with delays often makes an important distinction between directive and intrusive parenting. Stevenson and Crnic (2013: 502) draw the distinction as follows: directive parenting reflects structure and control in both verbal and non-verbal interactions and activities, typically in conjunction with less choice and increased information or direction. An example would include instruction such as 'Say thank you' or 'Put the puzzle piece here'.

In contrast, intrusive parenting refers to verbal or non-verbal behaviour that restricts the child's activity, attempts to force the child to engage in an activity despite his negative reaction or disinterest, the continuous presentation of toys, or the overbearing interaction that does not allow the child the opportunity to respond. As key difference between these parenting styles, these researchers point out that despite intrusive parenting also being directive in nature, it does not obstruct the activities; whereas intrusiveness does.

In terms of appropriateness in the parenting style in the case of a differently abled child, Baker and Crnic (2009) suggest that in parenting the differently abled child, focus is often less on emotion and more on coercive interactions. In this regard, Floyd, Harter, Costigan and MacLean (2004: 508) draw the attention to the tendency toward lack in synchronicity and positive reciprocity within both general interaction and specific problem-solving contexts.

Green and Baker (2011: 325) maintained that the preferred parenting approach does not necessarily indicate less affection or warmth of the parent and therefore does not necessarily negatively affect a child's development. Indeed Stevenson and Crnic (2013: 502) suggest that more directive parenting may be a better match to the special needs child's understanding and behaviour in a given context, and thus may result in improved

child compliance and therefore less parent-child negative interactions; whilst intrusive parenting may undermine the child's ability to explore their environment, their autonomy and diminished self-regulatory skills.

Findings by Stevenson and Crnic (2013) indicate a particularly salient role of fathers' intrusive approach as a risk factor for the development of self-regulatory and social abilities in children with developmental delays. Although their study shows that fathers who were more intrusive when interacting with their children in the home had children who later showed decreased social skills, the connection appears to be indirect such that intrusiveness leads to more dysregulated behaviour in children, which in turn adversely influences the children's subsequent social skills.

Stevenson and Crnic (2013: 507) further point out that this particular pathway of influence is noteworthy considering that it occurs above and beyond mothers' intrusive behaviour. With the dearth of empirical studies on fathering of children with developmental delays, their study highlights the unique risk of intrusive fathering to the child's self-regulation and social development.

2.10. WHO IS THE IDEAL FATHER?

Sririam and Navalkar (2012: 206) consider the increased knowledge through psychological and contextual research to be accompanied by a growing recognition that much of parental cognition is itself socially or culturally organised. A question like 'Who is the ideal father?' is typically a socially constructed question with substantial links between beliefs and behaviour as well as culture transmission and change (Arendell, 2000: 1192). According to Sririam and Navalkar (2012: 205), fathers are most influenced by their own parents in their ideals, followed by close relatives and other sources such as the media, mythology, friends and their respective spiritual orientation.

So far, this chapter has provided evidence of change in the ideologies surrounding fathering. Although discourses of new fatherhood call on contemporary fathers to enact the dual roles of financial provider and engaged caregiver (Marsiglio & Pleck, 2005: 249), more recently Plantin (2007: 93) questioned the usefulness of these popular discourses by recognizing that the socio-economic status of fathers are likely to affect successful enactments of new fatherhood ideals. Supporting this notion, Lautsch and Scully (2007: 727) concede that, given their choice between 'money *or* family' and 'money *for* family',

low-income and working-class fathers may experience specific challenges to fulfil 'new father' expectations.

Stereotypical conceptualisation of 'good fathers' describe fathers as being the sturdy oaks of the family, someone who is strong, reliable, powerful, consistent, offering a less emotional and more practical perspective on family problems. In contrast, Lamb and Lewis (2004: 28) pointed out that 'good fathers' may indeed also be patriarchs, disciplinarians, their children's best friends, playmates, moral leaders and educators. Unjustly the perception is often that fathers who are unable to carry out these roles are deemed as 'bad fathers' (Sririam & Navalkar, 2012: 207).

In the innovative compendium, *BABA: Men and fatherhood in South Africa*, Morrell and Richter (2006: 2) introduced this topic in rather pallid terms, saying, "Not all fathers are proud to be fathers, and unfortunately not all fathers want to participate in the lives of their children. Many seldom attend the births of their child, or don't always acknowledge that their children are their own, and they frequently fail to participate in their children's lives." Almost no literature exists on the topic of being a father in South Africa and the vast diversity within this spectrum would call for a separate research study altogether.

Understandably, different cultures interpret fatherhood in different ways. Morrell (2006: 23) confirms that over decades their interpretation of responsibility to provide and protect have forced many fathers to work away from home for a variety of reasons. However, for other, another way of interpreting fatherhood includes a more present kind of fatherhood in which their children are a part of their identity. Conditions that place constraints on how fathers understand and express fatherhood may also include individual and/or collective histories and material conditions, as mentioned earlier.

Research results showed clearly that parenthood and family are important to South Africans. A related national survey of individuals aged 18 to 32 years of age found that more than seventy percent of South Africans across all race groups and both genders ranked aspects of parenthood as their top defining features which characterise adulthood (Emmet, Richter, Makiwane et al, 2004). Despite pervasive negative fatherhood images of especially African men (Richter, Manegold, Pather & Mason, 2004: 18), Morrell (2006: 23) concedes that South African young men are increasingly speaking out about their desire to be good fathers, and are beginning to reassess the value of fatherhood. To this end, the Human Science Research Council fatherhood project acted as a catalyst releasing strong support for men as fathers.

Globally, the new dad image is interpreted as the father who fulfils not only the role of provider, but also fulfils a caring and nurturing role. Sririam and Navalkar (2012: 207-208) position fatherhood roles as follows:

- *Biological Fatherhood*: Acknowledgment of paternity and taking responsibility for welfare of children;
- *Economic Provider*: Assuming responsibility for making appropriate levels of economic resources available to the child;
- *Partnership/‘The New Father’*: Providing his partner with physical and emotional security, and working together to provide emotional, economic, educational and other developmental needs of children, i.e. although man and woman both work, they share nurturing tasks and family life;
- *The Hands-on/Care-giving Modern Father*: In this instance both man and woman participate in childcare, although their participation may not necessarily be fifty-fifty. The man in this category is not necessarily in control, but learns and participates in an expressive, loving and caring manner;
- *The Enlightened Father*: This father *understands* the benefits of involvement and shared parenting. This father fulfils his role in awareness and practices mindful parenting as he recognises and acknowledges the positive results of increased male participation for certain aspects of family.

In response to the ideal father question, Morrell (2006: 23) said: “Masculinities which value both responsibility and caring should be fostered. Such masculinities should steer away from stereotypical claims that fatherhood gives men power over women and children and justifies authority and tyranny. Fatherhood can make a contribution to the lives of men and give meaning to their lives and open up unexplored channels of emotional engagement. When men accept the fatherhood role, in whatever form, they also contribute to the broader goals of gender equity. Fatherhood should be a role that integrates men into families, rather than separating them from children, women and other men.”

2.11. RESPONSIBLE FATHERHOOD

According to Fagan and Kaufman (2013: 3), early attempts to conceptualize fathering were intended to define what it means to be a responsible father relevant to married and unmarried fathers. For example, Levine and Pitt (1995) defined a responsible father as a man who: waits to make a baby until he is prepared emotionally and financially to support his child; establishes his legal paternity if and when he has a baby; actively shares with

the child's mother in continuing emotional and physical care of their child, from pregnancy onwards; and, shares with the child's mother in the continuing financial support of the child, from pregnancy onwards.

Doherty et al (1998) developed a similar model of responsible fathering for married and unmarried fathers that included four components as follows: establishing paternity; being present in children's lives; providing economic support; and, being directly engaged with children. For the purpose of this study we look at the four-part framework developed by Cranfield (1999: 43-55) to provide a summary of the growing body of empirical literature on fathering. This framework serves as a valuable guide for exploration of the essence of responsible fatherhood and includes the following dimensions: involvement, consistency, awareness, and nurturance.

- **Involvement**

One of the most significant contemporary perspectives of fatherhood revolves around the concept of father involvement. For the purpose of this study the term father involvement refers to the father's functional and social involvement in a child's life as proposed by Dyer, McBride, Santos and Jeans (2009: 266): functional involvement refers to a father's physical and hands-on participation in different therapies (for example speech and language therapy, occupational therapy and physical therapy), while social involvement refers to the father's engagement in different leisure activities (such as reading, singing, and engaging in play) with his child (Ansell et al, 2016: 2).

Lamb (2010: 3) divides active involvement of fathers into the following three components. The first involves interaction or engagement where the father spends time in direct person-to-person interaction with his child. As the second component, accessibility refers to the time a father spends in close proximity to his child, but does not necessarily involve direct interaction with the child. The third component of father involvement is labelled paternal responsibility and is related to the extent of the father's accountability for the child's well-being and care. Although men tend to be more involved with their children in terms of the interaction component of father involvement, Pleck and Masciadrelli (2004: 239) pointed out that increasingly men are also incorporating the other components of father involvement into their paternal conduct.

Rearing a differently abled child may mean extra demands on individual family members and on the family as a system (Nicholas 2013). According to Schieve, Blumberg, Rice,

Visser and Boyle (2007: 114) parents of a differently abled child generally experience poorer well-being relative to parents of typically developing children. Yet, it is possible for the father in this situation to be a potential resource for the family in terms of his positive involvement.

Research suggests as follows: father involvement may mitigate physical and emotional burden experienced by mothers (Pelchat et al, 2003: 231); it may bring about greater parenting competence and reduce stress for fathers (Elder, Valcante, Won & Zylis, 2003: 274); and, result in greater child gains in adaptive skills (Flippin & Crais, 2010: 25). Positive father involvement is associated with greater socio-emotional, cognitive and behavioural child outcomes (Lamb 2010: 12).

Pleck (2010: 101) affirms that positive paternal involvement requires high engagement, accessibility, and responsibility of the father, which indicates that both quality *and* quantity time must be spent with his children. Although there is no set formula for father involvement (Pleck, 2010: 102), it stands to reason that responsible fathers diligently search for ways to be actively involved in the lives of their children. Such a level of involvement with his child sends a strong message that a father cares about them and values them to such an extent that he would rather spend time with them than with anything else (Pleck, 2010: 102). Hence, active involvement on the part of fathers also models the value of commitment and responsibility for the child (Pleck, 2010: 102).

Louw et al (2008: 221) found that children's lives afford fathers numerous opportunities for involvement which include: helping with homework or coaching a sport team; feeding an infant or changing a nappy; taking the child to a park or to a mall; playing with the child or reading to the child; or, simply being accessible, being in the moment, and being actively present. Such examples of involved parenting practice indicates a shift from father involvement to father sensitivity with a focus on quality rather than quantity of time spent with the child (NICHD, 2010: 210).

Father involvement is also beneficial to the child as follows:

- Sensitive fathering involves responding to, talking to, scaffolding, teaching and encouraging their child to learn, is a predictor of socio-emotional, linguistic and cognitive achievements (Shannon, Tamis-LeMonda, London & Cabrera, 2002: 87);
- Children of involved fathers displayed increased internal locus of control, and fewer sex-stereo-typed beliefs (O'Connor & Scott, 2007);

- Indicated by both international and national research, children whose fathers are present and take an active interest in their activities achieve better at school, have higher self-esteem and are more secure in their relationships with partners of the opposite sex (Schacht, Cummings & Davies, 2009: 290-297; Carlson, 2006: 136);
- Increased cognitive competence was noted in children who have two highly involved parents which ensure diversity in stimulation through interaction with two individuals with different behaviour styles (Desforges & Abouchar, 2003);
- Paternal involvement in child care was found to be a significant predictor of empathy within children (Flouri & Buchanan, 2004: 130).

Father involvement has shown to be beneficial to the father in the following ways:

- Men who are involved fathers feel more self-confident and effective as parents; they feel more intrinsically important to their child; they find parenthood more satisfying, and they feel encouraged to be even more involved (Ancell et al, 2016: 2);
- Fathers who are involved in their children's lives are likely to exhibit higher levels of psychosocial maturity (Flippin & Crais, 2011: 25);
- Involved fathers appear to be less psychologically distressed, and are more likely to participate in the community and assume leadership roles in civic community organisations (Eggebeen & Knoetser, 2001: 382). Such family involvement is especially important for young children with disabilities (Turnbull, Turnbull, Erwin et al, 2010). Lamb and Laumann-Billings (1997) revealed that the involvement of fathers in the lives of these young children has been virtually ignored, yet there is evidence of positive outcomes in emerging literature (Flippin & Crais, 2011).
- Increased paternal involvement allows the father to satisfy his desire for closeness to his child while permitting the mother to have a close relationship with her child *and* to pursue career goals (Pleck, 2010: 66);

Although the many roles that fathers play in parenting their children may vary between active participation in every facet of their child's life, and concentration on one or two facets of raising their children, the outcomes of such involvement is likely to create warmer, richer and more satisfying relationships all around.

- **Consistency**

Responsible fatherhood is rooted in consistency. Noted child development theorist Erikson contends that one of the primary goals of early child development is to establish

trusting relationships with primary caregivers. However, trust, cannot be established without consistency (Swartz et al 2011: 126).

Responsible fathers build a trusting relationship with their children by providing consistent encouragement, consistent care, consistent protection, consistent discipline and consistent love (Swartz et al, 2011: 127). Being consistent implies that a father will be present during the good times and the bad. Consistency in behaviour on the part of fathers promotes a sense of security and confidence in children, which in turn, lays the groundwork for a healthy self-esteem (Pleck, 2010: 100).

- **Awareness**

Pleck (2010) argues that responsible fathers know their children and hence they are able to express an honest interest in their children's development from conception, extending into childhood and beyond. Being aware of a child's needs will help a father to be better equipped to meet those needs at various stages of a child's life (Swartz et al 2011: 126). Awareness, however, requires motivation and active involvement. As responsible fathers want what is best for their children, they make a concerted effort to get to know them. They further understand that every child is unique, each possessing a different set of physical, emotional, cognitive, and social characteristics and makes allowance for this individuality (Pleck, 2010).

- **Nurturance**

Within the context of a parent-child relationship, nurturance means to train, to educate, and to foster a child's healthy development (Swartz et al 2011: 127). In most cultures the concept of nurturing is almost invariably associated with the mother-child relationship. However, according to Green (2013: 12), fathers also play a critical role in the nurturing of their children by providing responsible and loving care that meets their emotional and social needs.

Louw et al (2008: 220) remind us that even though characteristics of responsible fatherhood and motherhood overlap, they are not identical. Research has shown that there are a number of gender differences in the parenting styles of mothers and fathers, with no one style necessarily superior to the other. For example, fathers tend to engage in physically stimulating and exciting activities that promote assertiveness rather than politeness (Louw et al, 2008: 221), hence, this type of interaction offers remarkable

benefits for both sons and daughters. The benefit further extends to both mother and father as it creates the opportunity to learn from the parenting response of the other.

It is clear that children need fathers who are committed to fulfilling their responsibilities to their children. There is an African proverb that says “It takes a village to raise a child.” But first it takes a mother and a father, who are compassionate, nurturing, understanding and responsible, working together to instil discipline, integrity, character, and responsibility in their children.

2.12. CONCLUSION

Most of the literature on fatherhood recognizes the influence of various factors. These include the structure of families (including marriage, paternity and co-residence); the quality of primary relationships (including the quality of the marital relationship; the relationship with the child’s mother, relationship with the father’s own father, the type of fathering relationship with the child, individual skill levels and motivation, the range and types of involvement, as well as the supports for and obstacles to involvement). Other significant factors which influence fatherhood are: financial status (employment and income); and, personal qualities (personality, health, educational level, parenting style, beliefs about the father’s role, and cultural background).

Chapter Two considered various theories on fatherhood as an essential point of departure on fatherhood per se. In this chapter the researcher drew a comparison between the traditionally defined fathering roles and the increased commitment of men to their families and the well-being of their children which hailed the twenty-first century emergence of the ‘new father’ as both provider and caregiver for his children. It is clear from the literature that a good father is one of the most unsung, unpraised, unnoticed, and yet one of the most valuable assets in our society.

Chapter Three will extend the fathering experience specifically to fathers of children with Down syndrome.

CHAPTER THREE

DOWN SYNDROME: A LITERATURE OVERVIEW ON ETIOLOGICAL BACKGROUND AND ASPECTS RELATING TO THE FATHERING EXPERIENCE

3.1. INTRODUCTION

When flying at thirty thousand feet, it is a fair assumption that every airline passenger secretly dreads hearing the announcement of the captain: “Ladies and gentlemen, we are experiencing a mechanical problem with the aircraft. Please remain calm and fasten your seatbelt...” Any parent who has ever heard a doctor explaining that their child has a significant disability may relate to this analogy. Both parent and passenger alike suddenly find themselves on a journey that is far from the expected. Both are fearful of the consequences of the next announcement. Both are faced with a situation over which they have no control. Both feel utterly powerless and helpless. But, whilst the plane passenger can only hope that the pilot will save the day, the parents really have only themselves to rely on.

Surviving the journey with a differently abled child requires more than just a strong seatbelt. It requires an inner strength that relies hugely on empowering oneself in order to maintain some control over circumstances. This necessitates information, knowledge and a measure of understanding of the ‘mechanics of the problem’ at this stage of their journey (Webber, 2011).

Chapter Three commences with an overview of the aetiology of DS. This will be followed by a summary of the most pertinent historical and contemporary perspectives related to research on fathers of children with DS. Following that, we will look at factors which contribute to the DS advantage, as well as the impact of the child with DS on the father. Issues related to the experience of grief, adjustment, adaptation, and coping is followed by sources of support available to the father. This chapter concludes with a comprehensive section which explores African perspectives on DS.

3.2. WHAT IS DOWN SYNDROME?

DS is a genetic-chromosomal disorder with its research history dating back to the 1860's (Hoffman, Sweeney, Hodge, Lopez-Wagner & Looney, 2009: 178) and confirmed by Urban, Stewart, Ruppelt and Geerts (2011) to be the most common genetic cause of significant intellectual disability (henceforth ID) in the human population.

Persons who have normal cell structures have 46 chromosomes, arranged in 23 chromosomal pairs, whilst a person with DS has 47 chromosomes, with extra genetic material occurring during formation of reproductive cells on the 21st chromosome (Patterson, 2009). It is purely a genetic chromosomal condition which knows no social, ethnic, socio-economic or cultural boundary. As it is not a sickness, it cannot be cured (Patterson, 2009).

The National Down Syndrome Society (2012) summarises some of the significant effects of the syndrome as follows: The effects of the extra chromosomal material vary vastly among and it is evident that the only thing they have in common is the syndrome itself (Stoneman, 2007: 1007). Persons diagnosed with DS have individual capabilities, talents, likes and dislikes; they attend schools, are employed, participate in decisions that affect them, and contribute to society in many ways (Stoneman, 2007: 1006). All people with DS experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents of such individuals. Specialized, high quality educational programs, a stimulating home environment, good health care, positive family support and an accepting community enable people with DS to develop their full potential and lead fulfilling lives (Stoneman, 2007: 1006).

The National Institute of Child and Human Development (2010) refer to three genetic variations that can cause DS: *Trisomy 21* is the most prevalent form of DS and simply means that every cell in the body contains an extra chromosome 21. In the case of *Translocation DS*, a fragment of chromosome 21 breaks off and attaches to another chromosome before or during conception. This type of DS occurs rarely and of all the types of DS, is the only one which is inherited (Patterson, 2009). *Mosaic DS* occurs when chromosomes fail to separate properly, causing a mosaic pattern of body cells. Such inappropriate cell division causes one cell to have 22 chromosomes while another may have 24 chromosomes. Dependent on the percentage of cells containing the extra genetic material, and the tissues in which these cells are located, a person with mosaic DS may exhibit all, some or none of the typical DS characteristics (Patterson, 2009).

Whilst statistics show that one in about 800 children is born with DS worldwide, research in South Africa suggests the figure of one in approximately 650 children in developing countries (Down syndrome South Africa, 2010). The incidence of births of children with DS increases with the age of the mother. But due to higher fertility rates in younger women, 80% of children with DS are born to women under 35 years of age (National Down syndrome Society, 2012).

Life expectancy of persons diagnosed with DS may generally be lower than the average, heavily dependent upon general health issues, nutrition, lifestyle, access and level of medical services, level of physical activity, integration and community inclusion (NDSS, 2012). Documented by Morris, Alberman and Mutton (2012: 1151) as the most common neuro-developmental disorder of known genetic cause, DS was recognized more than a decade ago as the sole genetic condition in which life-spans have doubled over the past 40 years (Shin, Besser, Kucik & Lu, 2009: 1565; Bittles & Glasson, 2004: 282).

DS can be established during pregnancy or after a child is born (Caughey, Hopkins & Norton, 2006: 614). *Prenatal screening* in the first trimester includes a blood test for certain proteins in the mother's blood and an ultrasound which detects nuchal translucency, the fluid at the back of the foetus's neck (Driscoll & Gross, 2009: 2557). According to Ehrich, Deciu, Zwiefelhofer and Tynan, (2011: 203), during the second trimester a triple screen blood test may detect levels of three different markers, and a quadruple screening for four. A combined test (integrated test) uses all tests from both trimesters in order to produce one DS risk rating (Driscoll & Gross, 2009: 2556).

A second step in diagnosis is *Prenatal Diagnostic Testing* which involves removing and testing a sample of genetic material, but carries a risk to the mother and foetus, which includes a 1 to 2 percent risk of miscarriage. According to Ehrich et al (2011: 203) three methods of prenatal diagnostic testing are used as follows:

- *Amniocentesis* is the process of harvesting a sample of amniotic fluid which is tested for the extra chromosome. This procedure can only be done between weeks 14 to 18 of the pregnancy.
- *Chorionic villus (CVS)* is done between weeks 9 and 11 of the pregnancy and involves a cell sample from the placenta which is tested for the extra chromosome.
- *Percutaneous Umbilical Blood Sampling (PUBS)* is the most accurate diagnostic method and can confirm the results of CVS and/or amniocentesis.

A sample of foetal blood, taken from the umbilical cord through the uterus, is tested for the extra chromosome. This procedure can only be performed during week 18 to 22 of the pregnancy.

According to Caughey et al (2006: 108), the diagnosis of DS at birth is usually initially based on evident physical signs of the syndrome, and is subsequently confirmed by a sample testing of the baby's blood to determine the number of chromosomes.

- **Primary features of Down syndrome**

Primary characteristics of DS include physical characteristics as well as intellectual and developmental symptoms. At birth, and afterwards as the toddler with DS develops, the number of known primary features present is not necessarily indicative of the individual's cognitive ability. Many of the features listed below may similarly present in any child, but only in children with DS does it occur with a degree of cognitive impairment.

In addition, Ulrich, Burghardt, Lloyd, Tiernan, and Hornyak (2011: 91, 1464) point out that physical development of children with DS is often slower than typically developing peers, hence, the gross motor development may be delayed due to low muscle tone. Despite these delays, children with DS can learn to participate in physical exercise activities and do indeed meet many of their developmental milestones; however, it may take a little longer than other children (A.D.A.M. Medical Encyclopaedia, 2012).

Although there are common physical signs of DS, not all of these may be present in all individuals diagnosed with DS. Similarly, not all individuals diagnosed with DS experience health problems. The symptoms of DS vary from person to person, and people diagnosed with DS may experience different problems at different times of their lives.

According to Bull and the Committee on Genetics (2011: 395) and A.D.A.M. Medical Encyclopaedia (2012), the following are common physical characteristics of people with DS:

- Decreased or poor muscle tone
- Short neck, with excess skin at the back of the neck
- Flattened facial profile, flat nasal bridge and small nose
- Small head, ears, and mouth

- Upward slanting eyes, often with a skin fold that comes out from the upper eyelid and covers the inner corner of the eye (epicanthic fold)
 - White spots on the coloured part of the eye (Brushfield spots)
 - Wide, short hands with short fingers
 - A single, deep, crease across the palm of the hand (palmar line)
 - A deep groove between the first and second toes (sandal gap).
- **Factors associated with the development of children with DS**

In terms of intellectual and developmental symptoms, mild to moderate rather than severe cognitive impairment is associated with persons diagnosed with DS according to Bull and the Committee on Genetics (2011: 396). Cognitive impairment refers to challenges with thinking and learning. As stated by CDC (2012) and A.D.A.M. Medical Encyclopaedia (2012), other common cognitive and behavioural problems may include short attention span, poor judgment skills, impulsive behaviour, slow learning and delayed language and speech development. Most children with DS develop adequate communication skills, though compared to typically developing children may take longer for them to do so. Martin, Klusek, Estigarribia and Roberts (2009: 129) recommend early intervention, coupled with ongoing speech and language interventions to encourage expressive language and improve speech.

Martin et al (2009: 129) affirm that in addition to intellectual and developmental disabilities, individuals diagnosed with DS are at increased risk for a range of health conditions, but that many of these associated conditions can be treated with medication, surgery, or other interventions. The following conditions are commonly found in children with DS: heart defects; vision problems; hearing loss; gum disease and dental problems, including oral-motor function difficulties; hypotonia; increased susceptibility to infections; a stronger likelihood for blood disorders (leukaemia); hypothyroidism; disrupted sleep patterns and sleep disorders including obstructive sleep apnoea; digestive problems (predisposed to Celiac disease); likelihood of epilepsy; weight issues; atlantoaxial instability; and, speech and language difficulties (Bull & the Committee on Genetics; 2011: 397-399).

Some children with DS may experience behavioural and emotional problems, including anxiety, depression, and Attention Deficit Hyperactivity Disorder. They might also display repetitive movements, aggression and certain strains of autism, psychosis, or social withdrawal. Although they are not *more likely* to experience these problems, they *are*

more likely to have difficulty coping with the problems in positive ways, especially during adolescence (Goldberg-Stern, Strawsburg, Patterson & Hickey, 2001: 375). Healthy friendships with peers support the emotional needs of children with DS, just as for typically developing children. Their needs and emotions are no different as confirmed by Buckley and Sacks (2002), and development, just like anyone else, is influenced by the quality of care, education and social experiences offered to them. Buckley and Sacks (2002) point out that puberty is reached at about the same age as any adolescents and that the physical, social and emotional needs of all teenagers and adults should be addressed in an age-appropriate manner.

Cuckle and Wilson (2002: 69) maintain that many adolescents with DS show significant progress during their teenage years, becoming more independent, responsible and applying what they have learned to activities that are deemed meaningful in their everyday lives. However, participation in life in an age-appropriate way is often hampered for the teenager with DS due to limited speech, language and cognitive skills. The limited research on fathers of children with DS necessitated inclusion of a number of dated citations in this chapter. The use of older sources also indicates the steady progress of noteworthy literature spanning several decades of research in the field of DS research.

3.3. DOWN SYNDROME: BACKGROUND ON THE FATHERING EXPERIENCE

It all starts with a diagnosis. Historically, the birth of a differently abled child was viewed as a tragedy. This view stigmatized the child as well as the entire family, according to Orphan (2004: vii). Until as recent as one hundred years ago, institutionalization almost without fail became the norm (Webber, 2011: 3-5). In contemporary times, children with DS are almost always raised at home within a family environment (Braddock, Emerson, Felce & Stancliffe (2001: 119). Despite a significant shift in parental (and societal) acceptance, some medical professionals still perpetuate the stigmatization of disability, with parents often reporting in research on unprofessional behaviour and advice from the medical fraternity (Virji-Babul, Eichman & Duffield, 2004: 120).

From as early as the 1930's parents of differently abled children have been advocating for the rights of their children, and in 1961 The National Association for Down syndrome was founded by a group of parents in Chicago. Limited external support and resources for parents of children with DS led to the establishment of more and more informal parent support groups which gradually became formalized and affiliated with larger organizations

(National Down syndrome Society, 2012). Although first world countries offer state assistance and support of well-established organizations, South African parents have to rely on non-profit parent support organizations such as Down syndrome South Africa (DSSA) and its affiliates.

Research on fathers of children with DS is limited. The methodological limitation of grouping together children with various disabilities has made it difficult to draw conclusions about the parental impact on families of children with DS from these heterogeneous samples (Hodapp, 2007: 280; Hodapp & Ly, 2005: 199).

Parents who have a child with DS have reported a number of comparative advantages in studies which compared families who have a child with DS to those who have a child without a disability. Parents of a child with DS noted the following: they are less likely to get divorced (Urbano & Hodapp, 2007: 272); their children are easier to raise (Marcovitch, Goldberg, MacGregor & Lojkasek, 1987: 249); and parents experience greater satisfaction with support from friends and community groups (Erickson & Upshur, 1989: 256).

Parents of children with DS and parents who have a child without disability have reported the following similarities: similar levels of marital satisfaction (Van Riper et al, 1992; Rodrigue et al, 1990: 376); they found no differences in stress levels (Stores, Stores, Fellows & Buckley, 1998: 235); their families are just as cohesive, adaptable, and communicative (Thomas & Olsen, 1993: 173); and they have similar levels of confidence in their parenting skills (Rodrigue et al, 1990: 376; 1992: 260).

Parents of children with DS have also reported the following comparative disadvantages: their children tend to have more behavioural problems (Gau, Chiu, Soong & Lee, 2008: 700); more time is spent on caregiving activities (Barnett & Boyce, 1995: 125); and some parents experience more stress, anxiety, and depression (Gau et al, 2008: 701). Across many studies, an increase in child behavioural problems was the most significant predictor of parental stress, if existing (Bourke, Ricciardo & Bebbington, 2008: 324; Most & Fiddler, 2006: 510; Hodapp & Ly, 2005: 200).

However, lacking from all of these previous studies is the perspective of contemporary fathers who have children with DS. In the next section we will look at what research in this regard has delivered up to now.

3.4. RESEARCH ON FATHERS OF CHILDREN WITH DOWN SYNDROME

3.4.1. Historical Perspectives

Much of the pre-2000 research was focussed on issues regarding the fathering experience of a child with intellectual disability (ID) and in many cases included reference to children with DS. Three major themes marked such research: the father's response to the diagnosis of his child with ID; the psychological adaptation of fathers of a child diagnosed with ID; and, the father's involvement in the child care of a child with ID. This section tracks these major themes and as this involves historical perspectives, hence includes many older references.

Father's response to the diagnosis

According to Hornby (1995: 253), fathers encountered intense reactions to the initial diagnosis. Murray, Sullivan, Brophy and Mailhot (1991: 225) revealed that fathers experienced loss of expectations in relation to their role as father, and due to the difference between their idealized and the actual fatherhood experience, they felt challenged to accept this role. This finding was confirmed in later studies by King and colleagues (2009: 59). Hornby (1995: 240) further maintained that fathers experienced co-occurrence of both negative and positive emotions; that fathers faced existential conflicts; and that fathers could experience personal growth through the process of adapting to their new situation of being the father of a child diagnosed with ID.

Studies that followed on Hornby's diagnosis response theme include findings by Bray, Skelton, Ballard and Clarkson (1995: 174): fathers felt that much-valued life goals were being disoriented and disrupted; along with a deep concern about their own capacity to meet any long-term needs of their child. Subsequent research by Pelchat and colleagues (1999: 394) confirmed this finding which also extended to the uncertainty of fathers regarding their own ability to meet the emotional and practical needs of their child, as well as the need of their families for emotional and practical support. Much later it would be observed by MacDonald and Hastings (2010a: 488), that, while the father was doing his level best to offer support to his family at this challenging time, his own needs were often going completely unrecognized, leaving him feeling peripheral and marginalized.

Psychological adaptation of fathers

The second theme of pre-2000 research focussed on the psychological adaptation to the fathering role related to children with ID. Grant, Ramcharan, McGarth, Nolan and Keady (1998: 58) noted two prevalent research approaches which governed this theme. The first approach was based upon the assertion that the child's diagnosis has a mainly negatively impact on the family, and hence, research mainly focussed on issues related to parental stress and depression. The second approach explored the psychological adaptation of parents by framing research questions around acknowledgement of potential rewards and positive experiences in raising a child with ID.

In comparative studies, Houser and Seligman (1991: 251, 252) distinguished no significant difference with respect to levels of child-related stress between fathers of typically developing children and fathers of children diagnosed with ID. However, their findings indicated that fathers adopted different coping strategies, and in this regard, fathers of children with ID tended to avert to distancing, escape-avoidance and positive reassessment more frequently than fathers of typically developing children.

Grant et al (1998: 59) found that the fathering role typically presents new challenges, marked by either possible positive or negative psychological outcomes for most fathers. In this regard, challenges of fathers of differently abled children were related to the father's individual experiences. Varying in intensity and nature, these challenges reportedly included: a deliberate balancing act of work and family responsibilities; association with complex service systems (such as health care providers, medical aids, education systems, and so forth); the possible acquisition of diagnose-specific specialized techniques in some cases (rare in diagnosis of DS without additional health issues); and, adapting to best cope with the range and of stressors experienced as a father and a husband.

In order to provide research evidence to either support or refute, Hornby (1995: 239-255) undertook a quantitative study focussed specifically on fathers of children with DS to investigate eight previous research assertions as set out below. The assertions are numerically indicated as headings.

1. *Fathers' adaptation to sons with DS not being as good as that with daughters:*

A limited body of supportive research evidence was found to justify this assertion and Hornby (1995: 247) concluded "that fathers' adaptation to daughters with DS did *not* differ significantly from their adaptation to sons."

2. *Fathers' adaptation is related to the severity of the child's disability:*

A study by Wishart, Bidder and Gray (1980: 375) found that fathers experienced more negative feelings and attitudes when their children were more severely handicapped, while the study by Tavormina, Boll, Dunn, Luscomb and Taylor (1981: 130) were concerned with the type of disability rather than the severity. Frey, Fewell and Vadasy (1989a: 55) and Frey, Greenberg and Fewell (1989b: 247) found that fathers' adjustment was related to the ability levels of their children, specifically to their child's competence with communication. Hornby's (1995: 247) research found that "fathers' adaptation was *not* related to the IQ levels, and therefore the severity of disability of their children with DS."

3. *The stress experienced by fathers is related to the age of the child:*

This assertion generated contradictory findings. For example, Cummings (1976: 252) reported lower levels of stress in fathers of older children than fathers of younger children with DS, whilst Gallagher, Beckman and Cross (1983: 17) found the opposite. A subsequent study regarding the effect of children with disabilities on fathers and mothers found that neither parent connected significant stress levels associated with the age of the child with the diagnosis (Beckman, 1991: 593). However, this particular study related higher stress scores to unemployed fathers as opposed to employed fathers; higher levels of neuroticism amongst fathers with higher stress scores; and lower levels of marital satisfaction amongst fathers with higher stress scores. According to Hornby (1995: 249), these findings suggested that "stress experienced by fathers is related to their employment status, their marital satisfaction and to personal variables, rather than to ages of their disabled children."

4. *Fathers' adaptation is related to their level of social support:*

Brotherson, Turnbull, Summers and Turnbull (1986: 215) and Meyer (1986a: 230) found that fathers' adaptation related to the *level* of their social support, whilst Frey et al (1989a: 55) later found that the adjustment of the father was related to his *satisfaction* with social support. Hornby (1995: 249) confirmed that fathers' adaptation was not related to the level of social support they received, but rather to their satisfaction of the support.

5. *Fathers' adaptation is related to their personal characteristics:*

Hornby's study found a significant link between fathers' adaptation and some aspects of their personality characteristics. This indicated that fathers who had higher levels of adaptation to their child with DS demonstrated low levels of neuroticism and high levels of social desirability. It also found that fathers with higher levels of adaptation experienced higher levels of marital satisfaction.

6. *Social class, educational level and income are inversely related to the stress experienced by fathers:*

Lamb and Frodi (1983: 450) and later Meyer (1986 a, b) suggested that lower-class parents were more adversely affected by the birth of a child with special needs than middle and upper-class parents. However, Faber and Rowits (1986: 220) argued that upper-class families experienced higher stress levels than lower-class families did in most aspects of functioning. The findings by Hornby (1995: 250) supported the assertion that perceived financial capacity and educational level were inversely related to the stress which was experienced by fathers of children with DS. However, Hornby's findings could find support for Faber and Rowits that fathers' stress related to their social class level.

7. *Many fathers experience depression and/or personality difficulties:*

Although earlier studies by Bristol and Gallagher (1986), as well as studies by Meyer (1986a) and Brotherson et al (1986) supported the assertion that many fathers of differently abled children experience depression and/or personality difficulties, later research conducted by Bristol, Gallagher and Schopler (1988) found "that there were no significant differences between such fathers and fathers of non-disabled children on a test of depression." This finding not only left the validity of such assertion open to doubt, but also dismissed the outcome of a study supporting such a notion conducted earlier by Cummings (1976). Hornby (1995: 251) pointed out that the latter was flawed by non-representative samples of fathers as well as unjustified author conclusions.

8. *Fathers of children with disabilities tend to experience considerable marital distress and desert the family more frequently than the average:*

Hornby's study (1995: 251-252) dispelled the contention that fathers of children with DS experience considerable marital distress and desert the family more frequently than the average. A frequently cited study by Gath (1977) supported the notion of elevated rates of marital difficulties and family breakdowns in families of children with DS compared to families without such a challenge. However, Gath and Gumley (1984) and thereafter

Hornby (1995) found no significant difference in marital satisfaction ratings between a group of *mothers* with, and without, children with DS.

Hornby's study (1995) drew the following tentative conclusions regarding the effects on fathers of children with DS: in all probability the fathers' adaptation is related to their marital satisfaction, to the satisfaction level of social support they receive, and to their personality characteristics, rather than the characteristics of their child; fathers do not experience greater levels of marital difficulties or divorce, personality difficulties or depression than other fathers. Although initially thought that the age of the child influences the stress related aspects of the father experience, it transpires that the experiences of these fathers is related to marital satisfaction, personality characteristics, education level, employment status and perceived financial adequacy.

Fathers' involvement with child care

Breslau, Salkever and Staruch (1982: 181) pointed out that literature prior to 2000 seemed to emphasize gender role differentiation among parents of children diagnosed with ID. According to Deutsh, Lussier and Servis (1993: 1160), couples raising typically developing children where the father plays a significant role in child care, showed more relationship satisfaction and also more contentment with such an arrangement than couples with more differentiated roles regarding child care. Willoughby and Glidden (1995: 404) added that, within the field of ID, the participation of fathers in child care appeared to impact how both parents evaluated the burden of care of the child. In this regard, participatory involvement of the father increased positive family coping and relationship adjustment for both mother and father.

According to Pelchat et al (2003: 238) differentiated gender role division (with mother immersed in her role as primary care giver, and often also as therapist) may cause inadvertent withdrawal from the father. This may result in the mother harbouring feelings of resentment for having to bear the entire burden of care which can ultimately result in relationship and marital conflict. Many couples reported a positive repositioning of their relationship as a result of high support (Pelchat et al, 2003: 239) which confirms findings of Bristol et al (1988: 450) that "disharmony" between perceived and desired support from one's partner was found to predict poorer parental adaptation.

In terms of polarized parental roles in a home with a child diagnosed with ID, Schilling, Schinke and Kirkham (1985: 860) noted how one parent, usually the mother, takes on the

care-giving role, whilst the other parent, usually the father, is drawn to the role of financial provider. Heller, Hsieh and Rovits (2000: 412) suggested that fathers of children with ID were less involved in housework and child care than fathers of typically developing children. This was noted as a lifelong pattern, often even after the husband retired from the workforce.

Lillie (1993: 439-440) found that fathers of children diagnosed with ID showed more interest in the needs of their child than historically surmised; that fathers were often disagreeable in female-dominated service systems; and, that role differentiation between parents did not really encourage much direct contact between father and child. The latter was mostly due to many of the child related activities, meetings and therapies usually taking place during the father's working hours.

The early literature projected a predominantly negative image of the effect on parents related to having a child with DS. Whilst we are aware that father-focussed research was nominal before 2000, it would be unrealistic to presume that such a profound event would *not* affect one deeply, as person and as a parent. It would further be remiss to assume that *all* fathers share identical positive and negative perceptions and experiences. Contemporary research drew the attention to the individualistic experience and perception and focussed on the father as an individual system as well as an inextricable part of the family system.

3.4.2. Contemporary Perspectives

Although considerable correspondence is noted between research on fathers of children diagnosed with ID before and since 2000, the post 2000 era saw empirical inquiry extend expansively into the psychological well-being of fathers. This section looks at the five dominant themes of contemporary research namely: psychological well-being of the father; delineation of gender specific experiences related to parenting stress; the impact of socio-economic circumstances on father adjustment; exploration in the use of psychological processes; and, fathers functioning as part of a partnership responsible for raising a child with intellectual disability.

Psychological well-being of the father

Psychological well-being refers here to psychological functioning for example depression, anxiety, self-acceptance, mastery, and so forth (Cuskelly et al, 2008: 106). In this regard,

research was focussed on parental stress and depression, reaching general consensus that parents of children with DS experience higher levels of parenting stress than parents of typically developing children (Olsson & Hwang, 2008; Stoneman, 2007). Oelofsen and Richardson (2006: 9-10) found that, coupled with the usual parenting stresses, the addition of having to deal with the adjustment and acceptance of an unexpected diagnosis elevated levels of parenting stress of a child diagnosed with ID. They further found that stress levels were elevated by accompanying challenges such as having to explain the child's specific challenge to others, having to extensively research their child's disability, and having to investigate and secure support (which may include specialized care and treatments for their child). Van Riper (2007: 117) asserts that parenting responsibilities, child demands, and psychological outcomes are related.

Most of the documented research on fathers of children with DS shares similar findings. For example, Ricci and Hodapp (2003) found that fathers of children with DS reported less child-related parenting stress, but similar parent-related stress, with also no significant difference in terms of involvement with their child. However, a definite marker for elevated stress in fathers of children with DS and other disability groups are challenging behaviour displayed by their diagnosed children (Cuskelly, Hayes & Grace, 2007; Abbeduto, Seltzer & Shattuck, 2004).

Glidden, Billings and Jobe (2006: 960) found individual paternal coping to be a predictor of the level of distress experienced by fathers, defining coping as a distinctive behavioural style or as a fine-tuned accommodation to an event requiring both behavioural and emotional responses and regulation. Stoneman and Gavidia-Payne (2006) confirmed the association between problem-focused coping and positive perceptions of fathers of children with DS.

Frey et al (1989a: 39) noted that in families with a child with ID, the mother tended to solve everyday care problems of the child, while the father tended to focus on problems outside of the family system. Hence, the father found to be more exposed to situations supporting his initiative, self-confidence and satisfaction levels. In turn, this was likely to contribute positively toward his individual adjustment and thus filter through to his co-parenting relationship.

Delineation of gender specific experiences related to parenting stress

Salovlita et al (2003: 300-312) found that although mothers and fathers attributed their stress to their own negative definition of their situation, fathers viewed the level of social acceptance of their child by family and friends as a significant predictor of their own stress. In a study aimed to demarcate gender specific factors that contribute to parenting stress (from a population sample consisting of parents of younger children) of Trute and Hiebert-Murphy (2005: 223), mothers reported higher overall levels of parenting stress.

The aforementioned study also found that fathers' stress over time related to their parenting morale, including confidence and enthusiasm associated with specific parenting tasks or parenting functions. Confirming earlier findings of Houser and Seligman (see 3.4.1), this study further pointed out that lower levels of social exposure and social acceptability of their child motivated higher personal stress experiences in some fathers, who would then find solace in an externally manageable situation such as their work.

Although Einam and Cuskelly (2002) suggested that, as a direct response to their sense of obligation towards the needs of their family, some fathers either reduced their working hours; other fathers were found to work considerably more hours than required. This was confirmed by Warfield (2005). Kersh, Hedvat, Hauser-Cram and Warfield (2006: 890) pointed out that difficult child temperaments are associated with increased levels of stress and depression in fathers of children with developmental disabilities.

The impact of socioeconomic circumstances on father adjustment

A study conducted by Olsson and Hwang (2008: 1110) regarding socio-economic issues reveal that hardship rather than income was related to the well-being of especially fathers of children diagnosed with ID. Hardship refers to goods and services that is both necessary and nice to have, but is simply not affordable.

Although having a child with DS does not appear to be influenced by or influence the socioeconomic status of the family, MacDonald and Hastings (2010a: 503), postulate that infants of DS are more likely to be born to older parents who have already acquired financial resources and built social networks which may serve to cushion them from depression, which is often associated in the broader psychological literature with poverty and less effective social supports.

Exploration in the use of psychological processes

The inception of behaviour therapies hailed exploration into mindfulness and acceptance processes as an optional channel to facilitate parental coping with the demands of raising children with ID. Siegel (2010: 1) defines mindfulness as “being conscientious and intentional in what we do, being open and creative with possibilities, or being aware of the present moment without grasping onto judgements.” Thus, being mindful describes a state of awareness that enables us to be flexible and receptive and to have presence. Mindfulness supports a paradigm of moving forward, rather than away from difficult situations – a crucial factor in supporting resilience in a life which includes parenting a differently abled child. Related to the essential parenting role, Siegel (2010: 2) argues that human beings are built to nurture and connect with one another, finding meaning in life and being of service to others. However, without finding ways to build resilience (being present) for such a role, parents of a differently abled child are at risk of becoming overwhelmed in the moment, and of burning out in the long run.

Hastings (2002: 465) indicated that parents (and other carers) of children and adults with ID often avoid interaction with these individuals, especially if they display behavioural problems. In the case of ID, mindfulness-based interventions focus on increasing the ability of parents to *stay* in the present moment, and to *accept* and *observe* their own indifferent emotional responses, rather than withdraw from their child, or avoid interaction with the child. Results of mindfulness interventions documented enhanced parenting satisfaction; reduced parental stress; and, improved behaviour of the child with ID (Tiwari, Podell & Martin, 2008; Singh, Lancioni & Winton, 2006; Blackledge & Hayes, 2006; Dumas, 2005).

Fathers’ functioning as part of a partnership responsible for raising a child with intellectual disability

Simmerman, Blacher and Baker (2001: 335) pointed out that as important as it is to understand how fathers cope as individuals, it is equally vital to identify how they function within the parenting couple relationship, as it is clear throughout the literature that the relationship between father and mother is critical to its central role of establishing and maintaining the emotional climate of the family. Consistent with the understanding of the family as a system, the father’s involvement is significantly influenced by the network of family relationships (especially the spousal relationship) within which it is embedded (Seligman & Darling, 2007: 84).

It appears that the father-child relationship is more vulnerable to long-term damaging effects of parental disharmony than the mother-child relationship (Cummings, Goeke-Morey and Raymond (2004: 495). This corresponds with findings by Pleck and Masciadrelli (2004) concerning a reciprocal connection between higher levels of father involvement and harmonious parental relationship. Pre-2000 researchers Bristol, Gallagher and Schopler (1986: 448) coined the phrase 'harmonic responsiveness' to describe "in tune" and "out of tune" partners in a couple relationship that functions effectively in terms of harmonious giving and accepting of support. In this regards, research indicates that fathers typically rely more on mothers for partner support than the other way around (Kersh et al, 2006).

In terms of their perceived role, Carpenter and Towers (2008: 118) refer to how fathers of differently abled children have been viewed as 'the peripheral parent' (Herbert & Carpenter, 1994), 'the invisible parent' (Ballard, Bray, Shelton & Clarkson, 1997), 'hard to reach' (McConkey, 1994) and 'just a shadow', overlooked by practitioners and researchers, with support systems benefiting only the mothers (MacDonald & Hastings, 2010a: 486). Carpenter and Towers (2008: 218) noted that fathers felt that neither employers, education nor health professionals recognised the need of the father to be included in the family situation, making it difficult for them to assert their involvement, and hence, fathers involuntarily fell back on the nineteenth-century stereotyped role of provider and protector, adept to deal with a crisis situation, yet emotionally uninvolved.

MacDonald and Hastings (2010a: 486) refer to the confluence of several developments which served to shift the focus of research onto fathers of differently abled children. These are: the field of developmental psychology challenged the exclusive centrality of the mother in infant attachment; changing demographic trends setting a context for increased opportunities for fathers to become involved with their children (Pleck, 2010: 66), referring to women's increased participation in the labour force, which loosened the expectation that mothers automatically assume primary caregiving responsibility for the child, subsequently involving and encouraging fathers to step into more nurturing and caring roles for their children; and, lastly, the deinstitutionalization of differently abled persons since the 1980's.

In modern society children and young adults with intellectual and developmental disabilities, and specifically individuals with DS, typically reside within the family (Braddock, Emerson, Felce & Stancliffe, 2001: 119). Before 1980's it was deemed to be "a very bad thing" to have a child with DS, but after 1980's this perspective changed from

tragedy into a stress-and-coping perspective (Hodapp & Ly, 2005: 178), especially with the emergence of the *DS advantage* as explained below.

3.4.3. The Down syndrome Advantage

The DS advantage is a term which refers to a pattern of findings and outcomes which emerged from studies where children with DS are compared to children with other disabilities. The following are characteristic of the DS advantage: their families are described as closer, warmer, and more harmonious (Abbeduto et al, 2004: 250); their parents report experiencing less stress (Most et al., 2006: 502; Olsson and Hwang, 2003: 329); and fewer cases of depression (Blacher & McIntyre, 2006: 195; Abbeduto et al, 2004: 250); their fathers and mothers are more confident about their parenting skills (Rodrigue et al, 1990: 371) and claim that their children are easier to raise (Weinhouse, Weinhouse & Nelson, 1992: 56); their parents report more marital satisfaction (Rodrigue et al, 1990: 372) with more satisfying networks of support (Hauser-Cram, Warfield & Shonkoff, 2001); their parents experience less overall pessimism (Abbeduto et al, 2004: 251) and report more positive experiences (Blacher & McIntyre, 2006: 184) with fewer time restrictions (Olsson & Hwang, 2003: 240). Whether these differences are attributable to higher parental incomes (Stoneman, 2007: 1007) or maturity that comes with advanced maternal age (Corrice & Glidden, 2009: 266), or whether both are more likely among parents who have a son or daughter with DS, is unclear.

Stoneman (2007: 1015) confirmed the aforementioned findings, adding that the DS advantage disappeared when the contribution of family income was controlled statistically. Jacques (2003: 4-5) described the following positive recurrent themes that have emerged in research involving the experiences of families of individuals diagnosed with DS:

- Source of joy and happiness
- Increased sense of purpose and priorities
- Increased spirituality
- Source of family unity and closeness
- Expanded personal and social networks
- Increased tolerance and understanding
- Personal growth and strength
- Positive impact on others/community

Hodapp (2007: 281) related the continued focus on positive research to: the increased sophistication of models used to understand family functioning; the shift away from institutional care models; acknowledgement of the rights and value of individuals with disabilities within general society deviations in family structure; and, the growing recognition of the importance of family care in providing support into adulthood.

Positive perceptions or gains associated with being the parent of a child with ID keep surfacing (Blacher & Baker, 2007: 345). With the objective of gaining insight into what information could be shared with expectant couples during prenatal counselling sessions with parents expecting a child with DS, Skotko and colleagues undertook the largest study to date. This study was nested in a larger cross-cultural, epidemiologic research on family attitudes toward persons with DS (Skotko et al, 2011: 2336). The findings of this study provided some of the most recent findings in research related to families of children with DS. In addition, significant information was gained from an even more recent study conducted in Japan to explore the lives of families with children with DS. In order to avoid duplication, the researcher focuses on these specific literature contributions to provide the most recent findings regarding the impact of the child with DS on the father in the section to follow.

3.5. IMPACT OF THE CHILD WITH DOWN SYNDROME ON THE FATHER

Extrapolated from the aforementioned research findings (Takataya et al, 2016: 6-7; Skotko et al, 2011: 2343-2343), the following lists how fathers of children with DS identified their child's impact on their life.

Positive impact:

- Increased positive outlook on life because of having a son or daughter with DS (especially if the child has fewer medical problems and learning difficulties);
- Positive life lessons include increased patience, flexibility and acceptance, as well as father learning to be more empathetic, tolerant and kind;
- Increased and strong feelings of protective love for the child;
- Change in perspectives on what is important in life and gaining an appreciation and respect for differences in other persons;
- Observation of a good relationship between siblings and the child with DS;
- Fathers feeling empowered and thus able to advocate for their child;
- Increased respect for the mother of the child and improved relationship;

- Increased confidence in childrearing as a result of increased knowledge about DS in terms of having a perspective on the development of the child;
- Positive adaptation to the child and the diagnosis (positive attitude) provides fathers with a sense of value and increased confidence in their ability to be a father;
- Recognition of the good influence of the child and acknowledging that the child has changed their lives in a positive way.

Negative impact:

- The child with DS was uniquely putting strain on the marriage (11% of participants felt this way and most were related to significant medical conditions and learning difficulties);
- Embarrassment as a result of child's significant learning challenges or public behaviour;
- In some cases, a loss of friendships;
- Physical challenges in terms of physical exhaustion (yet this was reported to be outweighed by the father's overwhelming love for the child);
- Delayed bonding (in cases where the child was in the hospital for a prolonged period after birth);
- Buying into the 'stigma' mentality (if father perpetuated or maintained a negative image of disability or negative attitude of health care professionals influence fathers to think and feel negatively about their child).

Many of the aforementioned aspects relate to emotions of the father. Orphan (2004: 98) relates the words of parent to the similar intense and painful feelings when someone close to you dies: "The impact of a child with special needs is huge; it is very stressful. Every parent has a dream for his child. When you realise those dreams are not going to come true, it can be devastating. It takes a long time. You wonder if you will ever get over it." Although it is not the same, Orphan (2004: 98) describes it as the nearest human experience.

Likened to this level of grief, these feelings affect everyone in different ways; some feel it all at once, while others feel one feeling at a time. These feelings are often revisited at different points; they don't have a beginning, middle or end (Orphan, 2004: 99). Having discussed what we know about the fathering experience of a child with DS, the following section addresses the issue of grief.

3.6. DEALING WITH THE GRIEF

Every parent of a differently abled child is familiar with the one emotion that is frequently ignored by many or mostly actively hidden: grief (Dowling et al, 2004: 11). Grief is an inevitable and unique emotion and is reportedly experienced by almost every father of a child with DS. Although there has been no death per se, every parent of a differently abled child experiences grief - in this case it is not grief over a physical loss; it flows from the loss of ideas, dreams, hopes, and expectations – loss of ‘what might have been’ according to Dowling et al (2004: 11).

Grief involves passage through various sub-stages to reach the resolution of grief: acceptance. These stages are shock and denial; anxiety and fear; anger; guilt and shame. Some individuals may go through the stages several times, others may get stuck in one stage, or reach a stage of acceptance and drift back to one of the other stages as a milestone or situation resurfaces (Orphan, 2004: 99). For some, grief may be a protracted process; for others a brief spell. For some parents, the grief never stops; it just pauses now and then (Webber, 2011: 82). The parent of a child with DS experiences a different kind of loss; not only loss of what could have been or what should have been, but it includes anguish and angst about the future (Orphan, 2004: 98).

Swiss psychiatrist, Kübler-Ross (1969), conceptualized the five stages of grief in her book “On Death and Dying.” Although originally focussed on grief resulting from death, this has also been found to occur in response to other types of loss, such as having a differently abled child. Two terms for distinguishing loss have emerged in literature namely **stage grief** and **episodic grief**. Stage grief refers to reaction of loss due to terminal illness or death. There are between three and seven stages, with significant emotions, that most people pass through toward acceptance of significant loss (Dowling et al, 2004: 12).

Shock is often characterized by feelings of disbelief, confusion, bewilderment, out-of-body sensations and numbness. **Denial** is frequently part of the shock stage and allows the mind and body the opportunity to regroup until the reality of the situation becomes tolerable according to Friehe, Bloedow and Hesse (2003: 213), who add that **anxiety** refers in this context to the fear, anxiety and insecurity of the unknown, and is significant insofar as the discomfort forces redirection to action which is more positive. These emotions are what propels parents to fervently research DS meticulously soon after the diagnosis.

According to Dowling et al (2004: 12), **anger** facilitates the release of emotions which precedes acceptance and the parent can begin focussing on the present with more clarity. Anger should, however, be dealt with constructively lest it heightens stress and interferes with constructive problem solving. Dealing with anger is complicated for parents who have had their child diagnosed as differently abled, as the child is still with them as opposed to having passed away. Parents may at this stage experience feelings of **guilt** arising from both a sense of failure, and a measure of regret at the loss of expectations. However, such feelings serve no purpose and may result in relationship problems (Orphan, 2004: 100). Parents often compensate for such feelings of guilt by immersing themselves in the child's therapeutic and educational needs, often prioritizing only the needs of the differently abled child and neglecting the rest of the family. Thus, they ultimately compound feelings of guilt.

Acceptance can be defined as the acknowledgement of the reality of the child's diagnosis, and Nicoll (Dowling et al, 2004: 13) postulate that at this stage, families begin to re-organize their lives, re-focus their energies and get on with life. The diagnosis of DS is only the point of departure for the parent, and acceptance is not necessarily a destination. Engaging in their child's interventions often take the time and energy off grieving, yet such delay in grieving may result in delayed attainment of ultimate acceptance. A handful of parents never reach the place of acceptance.

Episodic grief is referred to also as chronic sorrow, mobile mourning or recurrent sadness. According to Friehe et al (2003: 214), the crucial variance between stage grief and episodic grief is that the latter is a continued process with no complete resolution and no predictable end, as it tends to be revisited at critical life junctures. This makes it more ubiquitous, unanticipated and cyclic. The mere presence of the child remains a constant reminder to the parents. However, as there has been no death, many parents do not associate such feelings with their child, but to the ongoing challenges presented, and not the individual. Thus, the parents detach themselves from the syndrome and not the person, which is favourable for long term event-focussed problem solving (Friehe et al, 2003: 215).

Mothers are prone to episodic grief as they are primarily involved in the day to day care, meeting of milestones and age-appropriate development of the child, whereas the grief of fathers is often related to comparisons between their child and society's idea of a typically developing child (Friehe et al, 2003: 217).

3.7. ADJUSTMENT AND ADAPTATION

In addition to the day-to-day child rearing challenges, fathers of a child with DS also deals with coming to terms with the child's condition, apprehension regarding the child's limitations, health and educational concerns, and planning for any future caretaking needs that this child may require (Orphan, 2004: 106). There are families who adjust easier and thrive, whilst others have trouble adapting to the increased stress (Flaherty & Gledden, 2002: 409).

Mandleco, Frost-Olsen, Dyches and Marshall (2003: 367) define **adjustment** as the response to events not presenting major hardships, thus requiring only minor changes in family (or personal) functioning. Adjustment, in this sense, can also refer to the initial response of the father to a major event, such as the DS diagnosis of his child. **Adaptation** refers to the response to major transitions or hardships that require fundamental structural or systematic changes in family (or personal) functioning (Mandleco et al, 2003: 367) - such as the many ongoing challenges associated with raising a child with DS.

Successful adaptation occurs when balance is achieved between the needs of the child with DS, those of each individual family members as well as the family as a unit. This type of adaptation is referred to as bona-adaptation. Should such adaptation not ensue, unsuccessful family (or personal) adaptation, or maladaptation, occurs. Successful adaptation is marked by high levels of parental well-being and overall family functioning, whereas low levels of parental well-being and poor overall family functioning is ascribed to unsuccessful adaptation (Mandleco et al, 2003: 368).

In the researcher's experience, the birth of a child with DS necessitates a process of adjustment and adaptation over time. During the adjustment phase the family makes immediate short-term changes to cope effectively with the additional demands of rearing a differently-abled child. This may include practical aspects such as (extra/ full-time or sleep-in) domestic help, finding suitable therapists and schools, joining a family support group, lift-clubs for siblings and gaining knowledge about the syndrome. Whereas a child with particular health needs would require specific adjustments in terms of time, duties, roles and immediate financial considerations. These adaptations are the family responses in an attempt to meet the demands in respect of both developmental and other unexpected stressors and strains (Dabrowska & Pisula, 2010: 268).

How the father thinks about what is happening to him as an individual (and his family as a group), has a powerful effect on the success in adjusting and adapting to potential stressful events, such as having a child with DS (Dabrowska & Pisula, 2010: 268). How the father defines and perceives the disability, as well as his capability to effectively cope with the consequential demands, is fused into this thought paradigm. His ability to develop positive, adaptive beliefs and meanings will increase the probability of a pro-active approach to life for himself, each member of the family, including the child with DS (Abery, 2006: 6).

The meaning a father attaches to having a child with DS is significant and it is likely to change over time. Perceiving the child as 'less than normal', 'sick' or 'less capable' may negatively affect family interactions and relationships, with each other and with the child (Dabrowska & Pisula, 2010: 276). Such negative meaning has been linked with over dependency on parents, as well as lower levels of competence, and poorer developmental outcomes for the individual with DS (Abery, 2006: 6). Whereas positive meanings and attitudes toward the child with DS ("Our child is so much like other children", "Our child has drawn us together as a family") serves as a powerfully mindful protective factor for fathers and families, helping to manage each situation, whilst consciously and subconsciously minimizing further stress and strain (Trute & Hierbert-Murphy, 2005: 223).

Viewing the birth of his child with DS as a positive event or a 'good thing' rather than interpreting it as catastrophic, presents a constructive space with less likelihood of developing resentment toward the child (Trute & Hierbert-Murphy, 2005: 218) Furthermore, such an approach lays the foundation for providing a loving, nurturing environment that positively facilitates the child's growth and development; also, a positive family atmosphere is likely to increase the overall development of the child's skills, attitudes, and values, ultimately enhancing the probability of later independence, autonomy and a higher quality of life, with understandable benefit to both the family and the individual with DS (Abery, 2006: 7).

The difference between demands, stressors, stress, and strain is defined as follows. **Demand** relates to an external stressor for example demands or transitions related to the child's initial entry to pre-school, elementary school, adolescence, as well as entry into the adult world of employment. This refers to normative events which are expected changes and transitions during the course of an individual's life cycle. They are to be expected and anticipated (Abery, 2006: 4). For the father, non-normative demands include extensive participation in early intervention programmes, weekly or even daily therapy, or the need

to meet with professionals, teachers and school psychologists (Abery, 2006: 4). Such demands impact the father because of the implied changes they bring to the intra-psychic subsystems of the father namely the emotional, cognitive, physical, behavioural and/or spiritual subsystems (or domains).

A **stressor** is any experience, event, or environmental stimulus that causes stress for the father. Such an event or experience is perceived as a threat or challenge to the individual and can be either physical or psychological, and can make individuals more prone to both physical and psychological problems, including heart disease and anxiety (Cohen, Janicki-Deverts & Miller, 2007: 1685). A stressor is more likely to affect the father's health when they are chronic, highly disruptive, or perceived as uncontrollable (Cohen et al, 2007: 1686), such as the diagnosis of his child and the subsequent challenges related to DS.

Stress for the father of a child with DS is a situation which manifests as a perceived or real imbalance between demands on the father's capabilities and his ability to respond adequately to such demands (Abery, 2006: 6). Stress is likely to affect every subsystem for the father and there is likely a connection between stress and illness (Ogden, 2007: 281). If the father experiences chronic stress and a lack of coping resources, this may lead to the development of psychological issues such as depression and anxiety (Ogden, 2007: 282). Chronic stressors persist over longer periods of time and tend to have a more negative impact on health because they are sustained and thus require the body's physiological response to occur daily. This depletes the body's energy more quickly and usually occurs over long periods of time, especially when these micro-stressors cannot be avoided, for example the stress of the daily challenges regarding the child's diagnosis.

Recent studies have found that it is not stress itself that causes the increased risk of illness, it is actually the *perception* that stress is harmful (Keller, Litzelman and Wisk, 2012: 681). For example, when the father is under chronic stress, permanent changes in his physiological, emotional, and behavioural responses are most likely to occur (Cohen et al, 2007: 1686). Stress can be perceived as eustress (when a stressor is perceived as positive - positive stress) or as distress, which is negative stress (LeFevre, Kolt & Matheny, 2006: 563). While distress is a threat to the father's quality of life and relates to when a demand vastly exceeds his capabilities (LeFevre et al, 2006: 564); in contrast, positive psychological stress can lead to motivation and challenge instead of anxiety (Keller et al, 2012: 682). A major event, such as the birth of a child with DS is likely to

cause distress initially, but may shift to eustress and motivate the father to become actively involved in the child's life (Gibbons, 2012: 28).

Strain refers to the actual negative effect resulting from stress, as may be experienced by the father (Lazarus, 2000: 665). Everyone experiences a measure of stress and strain, and despite applying best efforts to avoid it, prolonged periods of strain may cause the father's needs not being met adequately. With regard to strain, Abery (2006: 7) cautions the father to anticipate as far possible, to prepare contingency plans, and to implement such should the need arise, in order to alleviate or minimize the impact on himself and the family.

When a child with DS is born into a family, additional demands are placed on each individual system, as well as the family system as a whole. The mother and father both need to respond to the demands (physical and emotional) of their typically developing children and of the child with DS, which may require redefinition of roles within the family system. As primary care giver, the mother often experiences serious role overload related to this task, as the child with DS comes with a new set of demands in terms of hands-on care, therapists, possible health issues, and the like. Critical support from the father improves spousal relationships and, in addition, minimizes possible tension between parents and siblings of the child with DS (Van Riper, 2007: 124; Dowling et al, 2004: 124).

3.8. FATHER'S RESILIENCE AND COPING

Glidden et al (2006: 951) define coping as what a father *does* to achieve balance between the demands placed upon him, and the resources at his disposal. Fathers of a child with DS have a choice between emotion focused and practically focused strategies to deal with coping. Linked with resilience, practical coping strategies appear to yield positive outcomes (Buckley, 2002). These would include active problem solving strategies namely seeking information about DS, related services, and benefits and support available to the family; meeting other parents and joining a support group; and, making full use of family and community social support networks (Giallo & Gavidia-Payne, 2006: 946).

On the other hand, Buckley (2002) points out that emotion focused strategies include wishful thinking (maybe things will get better); passive acceptance (this is my lot in life and I have to put up with it); and, stoical thinking (making light of the issues without doing anything practical). Although emotion focused coping is reported to lead to stress and vulnerability, this may be an oversimplification of issues (Tanner Nelson, 2010). The type

of strategy that is positive may depend on whether it is possible to change a stressful situation or not, and the needs of parents at particular times (Glidden & Schoolcraft, 2003: 253).

According to Buckley (2002), factors that make families vulnerable are the following:

Family factors

- Poverty, poor housing, no car, and unemployment - these disadvantages make parenting more difficult in any family.
- Poor marital relationships, disharmony in the family.
- Personal resources, low self-esteem and self-confidence, passive and ineffective coping strategies.
- Poor parent-child relationship with child with Down syndrome - emotional ambivalence towards the child.

Child factors

- Difficulties with control and behaviour management.
- The demands of parenting a child with Down syndrome who has atypical difficulties such as:
 - Persistent behaviour or sleep difficulties
 - More severe developmental delays
 - Chronic health difficulties
 - Acute, life threatening, health difficulties
 - Difficult temperament e.g. restless, over-active, impulsive

Services and support

- Limited family and social support
- Inadequate services.

3.9. SOURCES OF SUPPORT FOR THE FATHER

Research suggests that the range of emotional and practical supports outside of the family influence family well-being (Buckley, 2002). The range of such supports is influenced by the individual personalities and coping styles of the father. For example, a father who does not have the confidence or may be uncomfortable relating to others in a group may not find any beneficial support within a support group setting. Seeking out social and practical support is generally described as helpful; all the research on coping

with stressful life events suggests that those who are socially isolated are more vulnerable and less likely to make positive adjustments (Boström & Broberg (2014: 817). For various reasons, having a child with DS often sets the family apart from others and may lead to social exclusion (Orphan, 2004: 13).

- **Social networks - church and community**

The father's existing networks of friends, at church and at clubs in the community can be a very positive source of support, provided that they are positive about the child with DS and welcome him or her into their homes or activities (Buckley, 2002). While some have found their church members and community a positive help, others have found some people in these groups to be negative and unhelpful (Takataya, 2016: 6; Mathebane, 2015: 181). It is to be expected that the beliefs that people have about disability and DS will influence their attitudes. Fathers have reported that they have had to educate those around them, including some service providers (Orphan, 2004: 14).

- **Parent support networks**

Not every father finds it useful to belong to a support group but for those who do it is important to find one that offers the kind of support that best meets their needs (Buckley, 2002). Fundamentally support groups provide understanding; the father does not need to give lengthy explanations as people already have an understanding of the context (Orphan, 2004: 25). However, the father who wishes to share his experiences and learn from others who have walked the road before may find joining a parent support group or DS association beneficial to meet other families with children with DS. However, not all fathers find organizations helpful (Skotko et al, 2011: 2342), and Takataya et al (2016: 7) found that fathers who tended to isolate themselves and their families rarely got connected with such groups recommended by healthcare professionals; rather, they appeared to prefer to do it on their own with great effort. According to Pelchat et al (2003: 241) fathers are sometimes reluctant to seek help or support because that would mean admitting that their child was different and had limitations, as well as confronting their own limitations as parents.

Some fathers reported that the most significant emotional and practical help that they received came from other parents. In the first months and weeks, parents often report that it was helpful to meet other families who have got over the shock and feel positive about

their child and the future. It was also helpful to see that they and their other children are leading ordinary lives (Skotko et al, 2011: 2341). In parent groups, parents benefit from the sense of mutual understanding and they benefit from the practical tips and advice shared by those with older or similar age children Buckley (2002).

- **A proposed chapter for fathers**

Pelchat and Lefebvre (2004: 124-131) designed a model for a holistic intervention programme for families of a child with a disability, supporting both mothers and fathers throughout the first six months of the child's life. It can be argued that, because of the inclusion of both parents, such a program would be suitable for meeting the initial needs of the father. Maintaining a positive perception of both the diagnosis and the child plays a vital function in supporting fathers to adapt to this life event, while the single most significant predictor of paternal stress is the negative definition of the situation (Salovlita et al, 2003: 309). Bearing this in mind, the researcher has a future view toward establishing a chapter specifically for fathers of children with DS.

Blacher and Baker (2007: 342) suggest that such a platform should support the father as an individual system, as part of a couple system, and as a parent. The emotional responses in every domain (subsystem) of his individual system are an antecedent to his adaptation to the new life circumstances as the father of a child with DS; hence, such support should ensue from the point of initial disclosure of the child's diagnosis.

Factors that mediate positive psychological adaptation to being the father of a child with DS may include assisting the father as an individual to develop his own skills and resources, and, to focus on cognitions about parenting in order to sustain his position as mindful head of his family (Blacher & Baker, 2007: 343). Mothers typically seek outside help during time of emotional need, whereas fathers may come to rely more on the mother (Salovlita et al, 2003: 309). For this reason, a chapter for fathers may encourage the combination of self-reliance and strengthening of the parental dyad in terms of open communication.

The purpose of such a group encounter would be: interaction with fathers who understand, yet continue to grow toward a deeper understanding of their own situation; to guide each other to gain insight into causes of conflict and stress; to assist in developing new and more effective ways of interacting and communicating about issues related to their child and DS; to learn from others who have been there before how to respond to

stressful events; and mostly, how to avoid becoming stuck in negative patterns of interaction (Rhodes, 2003: 59).

- **Information**

In the early days and months, one of the main things that fathers seek is information (Takataya et al, 2016: 6). Part of the shock and emotional turmoil associated with getting the diagnosis is that it plunges fathers into a world that they were not prepared for (Buckley, 2002). Most parents feel that they know what to expect when parenting a healthy baby, but once they learn that the baby has DS they feel at a loss and sometimes as if they are no longer in control of their lives (Takataya et al, 2016: 6). Accurate information about the baby and young child's needs and expected progress, and the availability of local services is usually reassuring and enables parents to begin to feel less distressed, to feel that they will cope and to feel more able to adjust positively (Buckley, 2002). Information can come in many ways at the present time. It may be written information, website information or verbal information from parents or service providers (Buckley, 2002). Fathers generally draw information about DS from the internet (Takataya et al, 2016: 7).

- **Friends and family**

In families that have a child with DS, fathers are generally perceived to provide help and support for the mother; however, although mothers indicate their appreciation of these efforts, they often feel that the father is not capable of providing adequate care for the child or that they are simply more qualified for this important task (Pelchat et al, 2003: 238). Such statements reveal the mothers' level of confidence regarding the fathers' parental abilities, and by being unsupportive, she thus undermines the father's concept of self-efficacy.

In terms of having time alone with their partners, fathers were attempting to spend more time despite the fact that caring for a child with DS left less room for intimacy (Pelchat et al, 2003: 240). In spite of this fathers were putting a strong emphasis on their marital relations.

Fathers expressed the same desires as the mothers to be in a relationship with a spouse, who was gentle and understanding, and would listen to them and respect them – typically

the kind of qualities a woman would be expected to manifest in dealing with others, but would be less likely of a male (Pelchat et al, 2003: 240). This illustrates the difficulties faced by men living through an unusual situation that has not yet been recorded in the catalogue of male societal role models (Pelchat et al, 2003: 240).

In terms of support, higher marital quality was related to lower levels of stress and fewer depressive symptoms for both mothers and fathers; and when the father participated in tasks and provided emotional support, mothers' perception of the caretaking burden was lighter (Cuskelly et al, 2008: 107). With regards to reciprocal emotional support, fathers appear to give the mother space when she is emotionally distressed; however, observing this increased the father's own distress (Takataya et al, 2016: 7).

There is conflicting evidence regarding the support of family and friends. While some fathers acknowledged that support by friends and family (relatives and extended family members) play an important role in assisting them to come to terms with the diagnosis and settle into their role as parent of a child with DS (Feldman, McDonald & Serbin, 2007: 616); others were dismayed by especially other male family members' clumsiness and uneasiness with the child (Pelchat et al, 2003: 240). However, it appears that, in comparison, female family members were comfortable and were generous in the support they offered (Pelchat et al, 2003: 7). These researchers also noted that fathers felt a greater need for support from their extended families than the mothers, even though it often did not take the form they expected (p 240).

An interesting finding by Pelchat et al (2003: 240) was that fathers recognised male shortcomings that they would probably have exhibited themselves, had it not been for their own experience with their child. Fathers who were confronted with what they perceived as bias from their families (or professionals) when their child was compared to others identified this as a source of undermining the child (Pelchat et al, 2003: 241). These researchers suggest that such stress may be more related to the marginalization and consequent stigmatisation that the disability generates, rather than the disability itself.

Other family members, particularly grandparents, play a central supporting role for many families (Skotko & Bedia, 2005a: 209). Little is known, however, about the needs of the father with respect to support, which indicates that more work on understanding how best to provide support for fathers is clearly needed (Cuskelly et al, 2008: 109).

- **Fathers' experience with the medical fraternity**

Majority of the time fathers who have children with DS only learn about the diagnosis after the birth of the child when the paediatrician or neonatologist is most often the person to answer this question. Infants with DS are easily recognized after birth on the basis of physical characteristics (short ears, depressed upper midface, palmar crease, and hypotonia), with confirmation via genetic karyotyping (Skotko, 2005: 64).

Many fathers do not have a positive memory of the delivery of the diagnosis as illustrated in the following anecdote: "In our case, we were told our daughter had Down syndrome about 2 minutes after she was born. She was still on the warming table, and a neonatal nurse shouted over her shoulder as she left the delivery room: *"Doctor, check the baby. I think she has Down syndrome"* (Leach, 2014). There are many similar 'horror' stories related to the diagnosis of their children (Virji-Babul et al, 2004: 113).

In this regard, a study by Skotko (2005: 67-70) revealed that physician's explanations are often insensitive or factually incorrect; information received about DS was not relevant to the infant's immediate health (in one case the doctor provided statistics about adult obesity and teen behavioural problems while delivering the diagnosis); medical staff members make excuses while delaying the announcement and/or paediatricians tried to shift the responsibility of conveying the information; mothers are often informed in a cold matter-of-fact manner about the diagnosis without the father of the child present; and, the diagnosis was conveyed to the parents while others were presents (this couple was told during visiting hours with everyone around, including their other children).

Some health care professionals make a case for their own preconceptions and have intimated that the birth of a child with DS was a regrettable happening. In this case, the doctor told the father right after his child was born that this could have been prevented or discontinued at an earlier stage of the pregnancy (Skotko, 2005: 71). Medical staff frequently refers to children with DS as 'these kids', 'Downs kids', a 'Downs' or, the most unacceptable, 'a mongoloid' (Skotko, 2005: 70). Although many fathers have shared negative stories about the diagnosis disclosure, it appears that physician behaviours seemed to improve with time, albeit slowly (Skotko, 2005: 74).

Fathers were grateful when their medical practitioners had some prior experience working (or living) with children with disabilities, and appreciate it when a doctor or nurse points out the joy in their child (Skotko, 2005: 75). One father said, "My paediatrician came into

my room after seeing my daughter and he said, 'She's beautiful.' That meant so much to me." Medical health practitioners often tend to spend time talking with the parents about the variability of the DS phenotype; however, parents prefer an approach towards discussing the impact of having a child with DS on the family (Hippman, Inglis and Austin, 2012: 39). Given father's stress relate primarily to social acceptability of their child with DS (Keller & Honig, 2004: 347), it is understandable that they prefer information conveying the similarities between persons with and without DS (Brasington, 2007: 732).

Fathers showed a clear preference toward information that provide a balanced perspective which includes positive and negative information (Sheets, Best, Brasington & Will, 2011: 1254) and believe that meeting families with an individual with DS is an appropriate way to gain a balanced perspective. However, Ahmed, Bryant and Hewison (2007: 319-320) maintained that it is more difficult to find parents willing to talk openly about their 'negative'-life experiences than finding those whose experience is more positive. It is clear that parents desire accurate and up-to-date information about DS (Skotko, Capone & Kishani, 2009: 755).

3.10. AFRICAN PERSPECTIVES OF DOWN SYNDROME

Relevant to this study, it is important to include the experiences of black Africans to provide an inclusive view on the perspectives of fathers. However, no literature was found on the black African father experience related to DS per se. In 2006, the Human Sciences Research Council compiled an anthology called 'Baba' about men and fatherhood in South Africa (2006). This collection examined fathers and fatherhood from many angles, yet the issue of fathers and disability was largely omitted.

The most closely related literature was garnered from a South African study aimed at indigenisation of social work which tracked the psychosocial effects of black African mothers of children with DS. Although the information was provided by mothers, it offers a significant glimpse into the phenomena viewed through the black African lens and therefore warrants inclusion in the current study. It is significant to note that the participants were recruited from existing DS support groups and included representation of the Tswana, Ndebele, Pedi, Xhosa and Venda ethnicity. The researcher acknowledges that other ethnic groups not represented here may have different cultural views, beliefs and practices.

Children with congenital abnormalities (often including intellectual impairment to a lesser or larger degree and also found in children with DS) are perceived generally as either a curse or the result of witchcraft in most black ethnic cultures (Cowles, 2003: 13). It thus remains a challenge for many black African parents of such a child to navigate between, and juggle the two worlds of the African paradigm and the world of professional assistance deeply embedded in a Western worldview (Mathembane, 2015: 170).

The following information and findings emerged from Mathembane's study (2015: 170-180) and provides contextual background to the black African parent (mother) experience of having a child with DS:

- At times of festivity, ceremony or a crisis in most African families, families belonging to the same clan pool their resources together both in cash and in kind, which contrasts with the Western individualistic value orientation to social functioning (Thabede, 2008: 235). This is underpinned by the basic values on which the African paradigm is premised and include, amongst other things, the following: importance of the family, importance of the group, respect for life and elders, fear of God, and a deep commitment to sustaining meaningful community life through shared produce, shared problems and sorrows as enshrined in the principle of *ubuntu/botho/xintu* (Tshabalala, 1991: 74). As briefly mentioned in Chapter One, *Ubuntu* refers to humaneness, "a pervasive spirit of caring and community, harmony and hospitality, respect and responsiveness, that individuals and groups display for one another" (Mangaliso, 2001:24).
- Values inherent in the traditional patriarchal family system include the philosophy of keeping family matters within the family (secrecy), and the traditional beliefs in ancestral powers and witchcraft which largely influence the mother's perspective and experience (Thabede, 2008:239).
- The African belief in sympathy militates against empathy in counselling, thus the idea of sitting up straight, having an open posture, and leaning forward and maintaining eye contact in the social work helping or family counselling process, are some of the common practices associated with the Western worldview, but alien to the African worldview (Tshabalala, 1991: 74).
- Stigma attached to giving birth to a child with congenital malformation or intellectual impairment, like DS, includes ancestral curse for some form of misdeed either by the parents or by the family as a whole (Christianson, Zwane, Manga & Rosen, 2002: 180) and incidents of gross neglect and abuse of children with DS or any other condition involving intellectual disabilities were reported to include children being chained and

locked up in houses for years by parents or families who did not want community members to see the child with disability (Rosenkranz, 2004).

- Serious challenges arise due to lack of resources and the inherent socio-economic inequalities that continue to prevail in black African communities, particularly those residing in deep rural areas, who are still trapped in extreme poverty with little or no access to basic resources and infrastructure (Mathembane, 2015: 172). This situation further complicates and frustrates parental efforts to provide care and support for the child with DS (Department of Social Development, Department of Women, Children and People with Disabilities and the United Nations Children's Fund, 2012).
- In addition to the overwhelming psychological reactions associated with discovering that the child has DS, raising such a child within a black African family is extremely difficult given the reality of widespread poverty and economic deprivation (Department of Social Development, Department of Women, Children and People with Disabilities and the United Nations Children's Fund, 2012).
- Parents do not always understand what DS is and they reported dissatisfaction with the overall experience of the diagnosis disclosure. Mothers were told that they had given birth to a child with some medical problem, but the shock prevented any further internalisation of information and hence they remained ill-informed about the condition even after various medical and allied professionals had spoken to them. Therefore they were also not in a position to explain the 'problem' to their families (Mathembane, 2015: 175).
- Consistent with findings from other studies (Takataya et al, 2016; Webber, 2011), most of the mothers were alone at the time of the diagnosis disclosure, and mothers expressed how they had wished in vain for family members to have been given accurate information in order to accept the situation and provide mutual support to each other as a family unit (Mathembane, 2015: 175).
- Compounding the trauma of the diagnosis, mothers reported that the abrupt information was often provided in a language other than their mother tongue, which resulted in some measure of comprehending that something was 'wrong' with their child, but unable to explain it to anyone else. This may also be influenced by the fact that there is no vernacular translation of the word DS in the African context. Furthermore, most of the words used to explain causes and mechanisms of DS (for example 'chromosomes') cannot be translated into the vernacular (Mathembane, 2015: 176).
- In terms of emotional impact, mothers found the experience particularly stressful, especially for the first few months. They were unable to cry or release their emotions

thus, as crying is a taboo in their culture while a person is alive; crying for a person is only permissible when mourning a death. Within the ethnic groups represented, there is the belief that crying for a living person may lead to the person dying prematurely (Mathebane, 2015: 177).

- As a coping strategy some parents relied on their belief in God and pastoral counselling while others tended to consult traditional healers, prophets, close family members and friends for support (Mathembane, 2015: 177).
- Many mothers disclosed that they were initially secretive about the condition of the baby in order to manage stigma, while others needed to first come to terms with the experience before exposing their child to others. This is consistent with the bargaining stage in the grieving process according to Kübler-Ross (1969).
- Mothers demonstrated courage and determination to face the challenges associated with having a child with DS and expressed their conviction to educate others about the condition. Perceiving their child as a 'gift from God', it appears that deep religious convictions influences parental adjustment to the child with DS, particularly with regard to how parents interpret and understand the presence of such a child in the family (Mathembane, 2015: 177).
- Contrary to findings of studies conducted in other countries that showed that the birth of a child was so traumatic that reproduction ceased in these families (Ando & Tsunda, 1978: 268), most participants in Mathemba's study continued normally with reproductive activities, with no significant gaps in childbearing that could be linked to the birth of the child with DS. Such uninterrupted sequence in reproductive activities amongst mothers may be an indication of their having accepted the situation and moving on normally, or it may also have been influenced by the high regard for life in the black African community (Mathembane, 2015: 178).
- Mothers resorted to self, family and friends to help cope with the psychosocial aspects of their situation (Cummins, Sevel & Pedrck, 2006: 27).
- Social workers mainly address practical needs such as assistance with accessing social grants (Mathembane, 2015: 178).
- Another area of assistance was arranging institutionalisation of the child if the social worker deemed this an appropriate course of action (depending on the severity of comorbid conditions). However, it appears that participants did not have a clear understanding why they should place their child with DS in an institution. According to Mathembane (2015: 179) the general negative attitude towards institutionalisation amongst the mothers, echoes an African proverb that says "*Tlou ga e imelwe ke mmogo wa yona*" (An elephant cannot be burdened by its own body part). Ryke,

Ngiba and Strydom (2003: 139) maintain that this refers to the divine responsibility of parents and not of institutions to look after their children as an extension of the “traditional cultural practices of black African people to keep their elderly persons with them.” Hence, there appears to be a preference amongst many black African people to utilise their extended family systems instead of institutional care on the basis of their belief of “not throwing away” their people (Ryke et al, 2003: 139). Such conviction evidently provided positive reinforcement to help mothers to accept and cope with their child with DS, including pooling of resources across the extended family system to care for the child with DS.

- Although some mothers were satisfied with the support they had received from their close family members (elders, partners and siblings), others reported that extended family members gossiping about the cause of the condition caused them much stress. It appears that some extended family members, particularly the in-laws have a tendency to attribute the condition to a curse by ancestors, while some attributed it to witchcraft by envious family members. Such negativity from extended family members negatively influenced the mother’s ability to cope with and effectively manage the situation (Mathembane, 2015: 179). According to Lea and Forster (1990: 218), “relatives, neighbours and friends may tend to pity, ignore or actively avoid the family.” This was confirmed by every participant in Mathembane’s study.
- An example of family stigmatisation is how the community negatively labels them was by calling their children ‘Zodwas’ (loners) after the name of the special school that their children attend. Furthermore, their children were isolated and generally not part of the pool of children in the community (Mathembane, 2015: 180). It thus appears that the stigma is attached to the whole family and not just the child. It appears that particularly extended family and other external parties such as friends and neighbours participated in labelling and stigmatisation, self-pity and mockery (Christianson et al, 2002: 180).
- Mothers found benefit in belonging to a support group insofar it provided assistance to explore the best ways of looking after their child with DS. They also acknowledged that support groups provided a normalising experience and go a long way in assisting them to come to terms with the psychosocial trauma created by the birth of a child with DS. They reported that, through the help of the support group, their relationship with their children improved (Mathembane, 2015: 180).

3.11. CONCLUSION

Becoming a father is an important developmental stage in the life of a man. We have seen up to now that when a child is diagnosed with DS an increased likelihood exists that the father may encounter additional dimensions in the stage of fatherhood, which may include unanticipated feelings, unforeseen experiences, and unexpected relationships. These are not necessarily only positive or only negative.

Research has for the longest time suggested that fathers of children diagnosed with ID (including DS), were mostly disengaged from the family; and were portrayed as peripheral figures living lives of silent desperation with limited or no option of alleviating their personal emotional distress. Despite the shift in the contemporary understanding of fathers of children with DS, this unique group of fathers, compared to the other family members, continue to be marginalized in the literature. However, significantly more is currently known about the perceptions, experiences and needs of fathers of differently abled children.

This chapter provided insight into the world of the father of a child with DS by looking at historical and contemporary perspectives. At the time of the diagnosis, fathers experience every emotion on the continuum, and although the child is still here, fathers experience the emotions likened to the stages of grief similar to losing a loved one to death. Indeed, the father grieves for the loss of expectation, dreams and 'what if'.

The importance of adjustment, adaptation, resilience and coping of the father is investigated and we looked at the different sources of support for the father of a child with DS. The last section of this chapter included a unique glimpse into the perspective of black African parents of a child with DS. The following chapter, Chapter Four, follows with an in-depth description of the research design and methodology followed in this study in order to provide answers to the research question.

CHAPTER FOUR

RESEARCH DESIGN AND METHODOLOGY

4.1. INTRODUCTION

The questions what, why, when, how, where and who constantly guide the researcher and informs the design and methodology throughout the qualitative study. According to Trafford and Leshem (2012: 91), these questions interrogate the series of decisions that comprise the researcher's strategy for conducting research. With this in mind, this chapter aims to provide an explication of the research plan and how it was executed.

4.2. STATEMENT OF RESEARCH PROBLEM

There is a common view that fathers of a child with DS are frequently left on the periphery of the family for a variety of reasons, as confirmed by Takataya et al (2016: 1). Not only does such a situation increase likelihood of negative affect on a father's perceptions about fathering, but consequently his actual fathering experience may be affected adversely under certain circumstances. The researcher acknowledges that this may not necessarily be the experience of every father of a child with DS. As pointed out in the background to this study (See section 1.2), some research has been carried out on issues surrounding this parenting situation; although majority of such studies have focussed either on mothers, or have contrasted the experiences between parents of children with DS to parents of children who present different diagnoses, or are typically developing. A search of the literature revealed that surprisingly little attention has been paid to perspectives and experiences of fathers who have a child with DS. So far no empirical research has been conducted on this topic within the South African context.

4.3. AIMS AND OBJECTIVES OF THIS STUDY

The specific objective of this study is to shed light on the perceptions, perspectives and experiences of South African fathers of a child with DS and to explore whether an effective platform of support could contribute toward an enriched fathering experience of their child with DS.

This study provides an important opportunity to advance the understanding of the perspectives and experiences of fathers of children with DS. The study aims to contribute to this area of research by exploring the experiences of fathers in order to further an increased understanding for fathers who are currently, and those who will be in future, in this situation; to create a framework to facilitate an enhanced experience for fathers of a child with DS; further a better; and, will serve to beneficially assist clinicians who break the news of the diagnosis and deal closest with the parents in the early days thereafter. Finally, the insights gained from this in-depth qualitative study should assist in developing strategies for national support organisations to prepare parents (especially fathers) for their new role.

4.4. RESEARCH APPROACH

- **Qualitative approach**

While there are currently two broad research approaches in the social sciences, namely quantitative and qualitative research, this study employed a qualitative approach. Denzin and Lincoln (2008: 4) indicate that “qualitative research involves the studied use and collection of a variety of empirical materials – case study; personal experience; ... life story; interview; ... that together describe routine and problematic moments and meanings in individuals’ lives ... Qualitative researchers deploy a wide range of interconnected interpretive practices, hoping to get a better understanding of the subject matter at hand.” Schurink (2008) notes that, for the researcher, each practice makes the world visible in a different way. Hence, more than one interpretive practice may be used in any study.

McNiff (2006: 310) and Henning (2007: 15) contend that it is the principles of social construction, the personal relationship between the researcher and the phenomenon and the situational constraints that influence and mould the investigation. They also state that the principles bring together the beliefs concerning the form and the nature of reality (ontology); the type of relationship association between the knower and what can be known (epistemology); and the way in which we get to know our world by various methods of inquiry, in an effort to develop a more accurate understanding of the world.

- **Objectives of the qualitative approach**

The most common research objectives underpin the qualitative research design as best suited this study (Johnson & Christensen, 2008: 34). These are: to explore the

phenomenon; to discover the perceptions, experiences and behaviour; and, to construct new knowledge in a narrative report with contextual description which includes direct quotations from research participants. At the core, this research provided a glimpse *into* specific behaviours, the reason *behind* specific behaviours and the *significance of events* for fathers of children with DS (Creswell, 2014: 186).

The following purpose key points support the qualitative approach as appropriate for this study (Lichtman, 2010: 7-8):

- It was the **researcher's intent** to study something that can be recorded as reality or truth. Hence, the pivotal key point underpinning the qualitative approach is that this study sought to further the **understanding and interpreting** of the beliefs, behaviour and social interaction (Barker, 2003: 406) as experienced and perceived by fathers of children with DS;
- **Data were garnered directly from the participants** by means of written responses to open-ended questions and own reflections. In contrast with precise measurement using structured and validated data-collection instruments to identify statistical relationships (used in quantitative research), the researcher identified patterns, features and themes during data analysis. Epistemology entails a general set of assumptions about the best ways of inquiring into the nature of the world (Fouché & Schurink, 2011: 309). Hence, the researcher believes that only by appreciating the lived experiences of the participants is she able to understand the perspectives and perceptions of fathers and understand the meanings they ascribe to it. Therefore, their own viewpoints and expressions are relevant sources of knowledge.
- The **group was small and participants were purposely selected**, thus multiple perspectives were gained from participants (rather than a single reality) despite a relatively small sample size (Creswell, 2007: 20).
- According to the nature of the reality criteria in qualitative research, **subjectivity is expected**. In line with the ontological orientation that everyone holds a different view on how reality should be understood and that these tend to vary on a continuum, the researcher acknowledges this range spans from an objective reality independent of human conception, to the notion of multiple, subjective realities that are socially constructed (Snape & Spencer, 2004). Not only does the researcher embrace the

continuous construction of reality, but also believes that it exist independently of peoples' understanding thereof.

Thus, she views the experiences and perceptions of fathers' challenges as real, which becomes meaningful as a result of their understanding of their experience of it. However, the researcher believes that their experiences are not only subjectively experienced, but that it is manifest within socially and contextually defined conventions of societal expectations of the role of the father. Thus, referring to the model of intra-psychic functioning of the individual, (See Figure 1.1), the external social systems effect and influence the internal domains of the father, and in a reciprocal and symbiotic manner, the functioning of the internal domains effect how he functions within the external social systems.

- The **role of the researcher is clear** and she is known to the participants. Recommended by Arzubiaga, Artiles, King and Harris-Muri (2008: 325), the researcher's identity was appropriately clarified to reveal the lenses and the degree of sensitivity with which she collected, viewed, analysed and reported the data. Her status has been unambiguous from the outset, as well as the intent to maintain an objective stance. The role of the researcher is discussed in more detail later in this chapter.
- **Participant characteristics are known to the researcher.** The researcher was clear on who would best provide rich information to answer the research questions, and participants were aware of the researcher's intentions with this investigation.
- **Characteristics of the qualitative approach**

The following section presents justification for the suitability of the qualitative approach for this study, based on the **characteristics of qualitative research** provided by Creswell (2014: 185-186).

- **Multiple sources of data:** Data for this study included the researcher's knowledge and experience, literature from related research and conceptual literature, and written responses (self-reports) from participants based on questionnaires (Creswell, 2014: 185).

- **Inductive and deductive data analysis:** Inductive analysis refers to the immersion in the details and specifics of the data to discover important patterns, themes, and inter-relationships. In other words the researcher started off by exploring and then confirming findings, guided by analytical principles rather than rules (Anderson, 2010: 6). According to Creswell (2014: 186), the qualitative researcher “builds patterns, categories and themes from the bottom up by organizing data into increasingly more abstract units of information.”

In this study, the researcher applied an inductive approach, not only in the analysis, but also while reviewing literature, as this requires investigating previous research from a different perspective (Gabriel, 2013). As such the inductive process required the researcher to work forward and backward between the themes and the data set until a comprehensive set of themes was determined. Then deductively, the researcher looked back at the data from the themes to establish if more evidence could support each theme or whether additional information was required. Although the process of this research began inductively, deductive thinking was necessary as the analysis proceeded.

- **Participants’ meanings:** The researcher’s attention remained on learning the meaning that the participants hold about the issue at hand and not the meaning that the researcher attaches to the research (or expressed in the literature) (Creswell, 2014: 186).
- **Reflexivity:** Reflexivity refers to the way in which the background of the researcher could shape the direction of the study (Creswell, 2014: 186). Referring to the circular relationships between cause and effect, and the premise that ‘knowledge cannot be separated from the knower’, the researcher remained vigilant to not influence the process and outcomes of this research. Constant referral back to the literature, supervisory guidance, and independent reviewers’ assistance in phases of analysis. The researcher acknowledges her ‘insider’ status, which generally impedes the intention to remain ‘outside’ their subject matter; their presence, in whatever form, will have some kind of effect. Indeed, this is one of the very reasons why the qualitative approach was chosen to answer the research questions of this study, as clarified before.

- **Holistic account:** According to Berg (2012), the phenomenon under study is understood as a complex system that is more than the sum of its parts; the focus is on complex interdependencies and system dynamics that cannot be reduced in any meaningful way to linear cause and effect relationships and/or a few discrete variables. In line with this, the researcher's aim was to develop a complex picture of the issue being studied. A larger picture emerged as the researcher reported multiple perspectives and identified the factors contained in the meaning that fathers made of their experiences and perspectives (Denzin & Lincoln, 2008: 57).
- **Natural setting:** A major characteristic of qualitative research is the opportunity and possibility of the researcher to collect data from personal interaction with participants by speaking directly to them and observing their behaviour within their natural environment (Creswell, 2014: 185; Creswell & Plano Clark, 2007: 30). Pertaining to this study, this aspect was indirectly facilitated by participants reflecting upon and formulating their written responses in privacy, thus within their own natural setting.
- **Researcher as key instrument:** Josselson, Lieblich and McAdams (2003: 4) assert the researcher to be the instrument of research in qualitative studies, and as such, the medium for the discovery and interpretation of meanings. With regard to knowledge, perspective, and subjectivity in data acquisition, the teacher acknowledges her distinctive function as key instrument. Capturing salient aspects to be included in this study included purposeful selection of participants to provide rich data, and relevant literature to answer the research questions.

The researcher's critical engagement with the data during analysis required the development of descriptive codes for patterns in the data which inductively generated larger themes. It involved constant critical interpretation of data, and relating these interpretations to other sources of insight about the phenomena, which included findings from related research, and conceptual literature (Barrett, 2007: 419). Hence, data analysis and interpretation relied upon the researcher's logic, artistry, imagination, clarity, and knowledge of the field under study. The final research report reflects primary evidence of the phenomenon interwoven with the researcher's reasoned interpretation thereof.

- **Emergent design:** Qualitative research relies on learning about the problem or issue from participants. Because multiple variables (such as the questions changing, forms

of data collection shifting, or a modification in participants) can influence the research, the initial plan for research cannot be tightly prescribed. The possibility of dynamic development makes the qualitative research process emergent (Creswell, 2014: 186).

The following are some of the **disadvantages of the qualitative approach** (Choy, 2014) which the researcher circumvented during the course of the study:

- **Researcher bias:** The researcher attempted to bracket her own views and perspectives throughout, by constant referral to the data and the literature.
- **Researcher bias in data collection:** This was minimised by extending the initial invitation to participate to a fairly large group, most of whom were names and not acquaintances as justified in the section under sampling. Redacting names on the participant responses and numbering these was beneficial.
- **Sources or subjects not all equally credible:** The researcher acknowledges that some participants were more likely to provide greater insight and understanding. Most participants provided elaborate rich data. Despite one pared response, the researcher did not doubt the credibility or sincerity of even one response.
- **Missing information:** Each participant completed every question and provided all the biographical information required by the researcher.
- **Participant trust issues:** The researcher already clarified the extent of transparency and honesty in presenting herself and the study to the participants. No trust issues were experienced or recorded from either party at any point in this study, or regarding this study.
- **Sample may not be representative of the population:** While the researcher acknowledges the relatively small sample size of this study, the participant diversity provided sufficient data to answer the research question.

4.5. RESEARCH PARADIGM

Denzin and Lincoln (2008: 11) maintain that research is guided by a set of beliefs about the world and how it should be understood and studied. Fouché and Schurink (2011: 308)

agree that “the existence of many different terms for basically the same thing causes a considerable degree of unnecessary confusion.” Kreuger and Neuman (2006) and Flick (2006: 141) refer to “designs”, while Barker (2003: 312) and Babbie (2007: 31) prefers the term “paradigm” when referring to basically the same thing: a pattern containing a set of legitimated assumptions and a design for collecting and interpreting data.

The researcher understands a paradigm to be a framework, viewpoint or worldview based on her own philosophies and assumptions about the nature of knowledge and the social world, how she views and interprets material about reality, and, the rules of procedure for the research study planned to best answer the research questions (Thomas, 2009: 72; Creswell, 2007: 19; Babbie, 2007: 43; Welman et al, 2005: 13). In the social sciences, the research material is the individuals or groups of human beings, viewed in different ways in different paradigms (Fouché & Schurink, 2011: 513).

Based on the concern to understand rather than explain the phenomenon under study through subjective exploration of reality from the perspective of the participants, the researcher considers the word *paradigm* to include these specific components: ontology, epistemology, methodology and methods. On the other hand, the researcher views the *approach* as how she dealt with the phenomenon, referring to the choice of the inductive or deductive, qualitative or quantitative approach.

The philosophical tradition followed in this research is of phenomenological, interpretive and constructivist nature. Constructivism is associated with subjectivity and it accepts the possibility of multiple realities, and rather than the verification of measurable, objective, factual data, the essence of constructivism is the intent to make sense of the meanings that fathers of children with DS have about their world (Creswell, 2014: 8). During this research process, meaning was co-created by means of the partnership between the researcher and the participants.

Furthermore, the researcher believes that it is difficult to go through a research project in a purist manner as some of the criticisms in any one approach is evident of the solutions in another and vice versa. In this regard, Creswell and Tashakkori (2007: 306) indicate that, in terms of worldviews, philosophical suppositions ought not to be viewed as absolute and inflexible.

- **Constructionism**

Constructionism is closely related to interpretivism. Constructivists believe that individuals seek understanding of the world in which they live; that these individuals develop subjective meanings of their experiences; and that these meanings are multiple and varied (Creswell, 2014: 8). The researcher employed a constructivist perspective by seeking a complexity of views rather than narrow meanings slotted into simplistic groups. This was also followed in the analysis process, by constructing codes and themes from the data. Complete reliance on the participants' view and the researcher's intent to understand how they constructed meaning of their specific fathering experience and perspectives, underpinned a constructivist perspective (Wilson, 2003: 248). Using the lens of the constructivist perspective, the researcher was able to understand the context of the participants, who provided this data by means of their reflective writ in response to carefully considered questions composed by the researcher.

- **Interpretivism**

The interpretive paradigm allowed the researcher to view the world through the perceptions and experiences of the participants (Thanh & Thanh, 2015: 24). In order to answer the research question, the researcher followed the interpretive paradigm to use the participants' experiences to construct and interpret an understanding from the gathered data (Neuman, 2009: 69). Specifically, interpretivism supported the researcher to explore the world of the participants by interpreting their understanding (Thanh & Thanh, 2015: 24).

Although the interpretive paradigm is not a dominant model of research, it is gaining considerable influence due to its accommodation of multiple perspectives and versions of truths (Thanh & Thanh, 2015: 25). These researchers consider interpretivism as inclusive due to its acceptance of multiple viewpoints from different individuals and from different groups. Morehouse (2011) believes that the acceptance of multiple perspectives in interpretivism often leads to a more comprehensive understanding of the phenomenon under study. According to Thanh and Thanh (2015: 26), this significantly facilitates researchers who need 'in-depth' and 'insight' information from participants, rather than numbers or statistics as favoured by quantitative researchers.

To explore the understanding of participants in this study, an interpretive methodology provided a context that allowed the researcher to examine what the participants had to

say about their experiences (Willis, 2007: 4). Thanh and Thanh (2015: 25) view interpretive research as more subjective than objective. Willis (2007: 110) argues that the goal of interpretivism is to value subjectivity, stating that “interpretivists eschew the idea that objective research on human behaviour is possible”. Linking to Willis’s points, Smith (2004: 42) perceives interpretivists as ‘anti-foundationalists’, because “there is no particular right or correct path to knowledge, no special method that automatically leads to intellectual progress.”

Researchers who employ an interpretivist paradigm predominantly use qualitative methods (Nind & Todd, 2011: 1) as qualitative approaches generally provide rich reports that are necessary for interpretivists to fully understand contexts. In the interpretive paradigm, the crucial purpose of researchers is to get ‘insight’ and ‘in-depth’ information. Relevant to this study, the goal of interpretivist research is to understand and interpret the meanings in human behaviour rather than to generalize and predict causes and effects (Neuman, 2009).

Creswell (2014: 200) adds that, in qualitative research, the final step in data analysis involves making an interpretation of the findings. This suggests that the researcher makes an interpretation of the data (which includes development of the participant’s experience description and analysis of the data for themes) and draws final conclusions. The essence of this interpretation is captured by asking, “*What* were the lessons learned?” The response to this question can be informed by several factors including the researcher’s personal interpretation based on aspects such as personal experience, history and culture; it could be meaning derived from comparison to findings found in relevant literature; or, it can suggest new and unforeseen questions raised by the data and analysis (Creswell, 2014: 200). Interpretivism has many variants, including hermeneutics, symbolic interactionism and phenomenology.

- **Phenomenological paradigm**

Specifying the philosophical grounds that guide this study, the researcher acknowledges the argument of Delpont, Fouché and Schurink (2011: 305) that the phenomenological researcher goes into the field with a framework of *what* will be studied and *how* it will be done. Phenomenology focuses on discovering and expressing essential characteristics of a certain phenomenon as they really are. Literally, phenomenology is the study of “phenomena”: appearances of things, or things as they appear in our experience, or the ways we experience things, thus the meanings things have in our experience. As it

attempts to understand the perceptions, perspectives and experiences of South African fathers of a child with DS (Delport et al, 2011: 305), this study can be seen as a phenomenological study. Furthermore, the findings were related to an existing body of theory and research (Leedy & Ormrod, 2005: 140).

Relevant to this study, Creswell (2007: 57) and Lichtman (2010: 79) expands the phenomenological study as a study that describes the meaning of the lived experiences of a phenomenon or concept for several individuals. At the root of phenomenology is the researcher's intent to understand the phenomenon under study and to provide a description of human experience as experienced by the participants in their life worlds, allowing the essence to emerge. This life world refers to the conscious experience of everyday life and social action (Schwandt, 2007: 315) and not a world or reality as something separate from the person.

This study's phenomenological perspective therefore rests on the culmination of the essence of the description of the experience of several individuals who have all experienced the same phenomenon. Using an interpretive approach provided the research greater scope to address issues of influence and impact, and to ask questions such as 'why' and 'how'. Thus, this phenomenological inquiry, as part of uncovering meaning, articulated 'essences' of meaning in fathers' lived experiences with their children with DS.

The phenomenological approach also informed data generation of this study via written responses from participants. Responding in their own language and words provided participants with an opportunity to describe and explain the essence of the phenomenon through expression of their feelings, fears, attitudes, needs, beliefs, thoughts, aspirations and needs regarding their own specific individual realities (Lichtman, 2010: 80).

4.6. ROLE OF THE RESEARCHER

"The qualitative researcher is a self-critical, thoughtful, curious and trustworthy human being – an instrument through which the world is studied. The depth and quality of the research depend on the skills and sensitivity of the researcher. Detachment and objectivity are neither possible, nor desirable" (Bless et al, 2013: 242). Typical to naturalistic research, this study relied on the researcher's skill to retrieve and interpret data, remaining empathetic, sensitive and unbiased (Poggenpoel & Myburg, 2003: 418). The sustained and intensive experience that the researcher shares with the participants

inevitably introduces a range of ethical, strategic and personal issues into the qualitative research process (Creswell, 2014: 187). This refers to instinctive bias and personal background which unavoidably shape the researcher's interpretations, adding that this also includes any ethical issues that may arise during a study.

Based on Creswell's (2014: 188) suggestions, the researcher adhered to pertinent aspects regarding her role in this study as follows:

- **Past experiences with participants:** The researcher's previous study was conducted in the Eastern Cape; the current study, in Gauteng. As a starting point, names were elicited from the list of families with children with DS known to the researcher, although none of these were family friends. Previous contact within this group comprised consultation with parents (mostly mothers) regarding developmental, educational or health related issues of their child with DS. A further list of names was drawn from the database of a local informal parent support group the researcher attended as a guest speaker on a previous occasion. This list was drawn up from memory several months after the researcher's single encounter with these parents. A number of parents were referred to the researcher by mutual friends or acquaintances, and a serendipitous meeting and subsequent conversation at a parent meeting resulted in the participation of two participants.
- **Transparency and disclosure:** To avoid compromising the study, the researcher needs to be explicit about how personal issues of instinctive bias or personal background may unavoidably shape the interpretation of data. Pannucci and Wilkins (2010: 619) define bias as any tendency which prevents unprejudiced consideration of a question, concluding that, in research, bias occurs when systematic error is introduced into sampling or testing by selecting or encouraging one outcome or answer over others.

The researcher shares Mehra's (2002: 2) view that, who I am determines, to a large extent, what I want to study; thus, in addition to social and historical position, a researcher's evolving self (in terms of the deliberate educational and professional choices that are made throughout their academic career) primarily influences selection of their research topics. Hence, the researcher has explicitly clarified personal connection to this research topic and made clear that this research study was driven by what the researcher wanted to know, not by what she already knew about the chosen topic. The researcher's ontological orientation is supported by Krieger's

(1991) argument that our external reality is inseparable from what we already know based on our lives and experiences (our inner reality) and thus the reality we all see is based on our understanding of the world, which, in turn, is based on our knowledge of the self.

According to Mehra (2002: 4), the researcher is an important part of the qualitative process and cannot separate herself from the topic/people she is studying. It is in the interaction between the researcher and the researched that the knowledge is created. Hence, researcher bias enters into the picture even if the researcher tries to stay out of it. During the current research the researcher behaved in as neutral fashion as possible, remaining aware of the power of the researcher in the dynamics of the relationship, and above all, she encouraged the participants to share their perspectives without requiring any approval or confirmation from the researcher. To this end, open-ended questions were posed that would not steer participants in a way which might appear to endorse a particular response, thus modelling a conversation between two trusting parties (Mehra, 2002: 6).

To prevent this research from being a narrative of her own opinions, the researcher employed the following strategies: Firstly, the reader was informed that the methodological framework of the study allows for interpretation resulting from the interaction and intersection between the reality of researcher and that of researched. Second, the researcher remained mindful of the possibility of personal bias, taking every possible measure to monitor subjectivity throughout the study. This was maintained through constant referral to the literature, keeping notes of own opinion, and critically reflecting upon those often, and discussion with her supervisor about issues that arose in this regard. The researcher constantly referred to her ontological view of multiple perspectives and interpretations, and consciously reminded herself that the participants are the experts on their lives, and that they are the ones who “have the knowledge” about the topic that she was interested to learn about.

Thus, the researcher’s explicit aim was to portray the reality of fathers of a child with DS, whatever side of the argument they were on, while maintaining appropriate protocol and integrity throughout the process. To ensure integrity of the study, the researcher maintained the following: an open and honest position with both participants and readers; clarity about the purpose of the study; clarified whose reality she wished to portray; and, adopted a narrative style of writing reflective of the context in which the study was conducted.

Acknowledging an inherent “insider” position in DS through her daughter, in order to avoid subjective bias, the researcher followed Mehra’s (2002: 11) recommendations above to keep the emic (insiders’/ participants’ voice) and etic (outsider/ researcher’s voice) voices separate as much as possible in the data. The decision prevailed to present the emic voice as predominant to tell the story, and the researcher endeavoured throughout to refrain from personal judgments or biased interpretations. However, the researcher acknowledges that the etic voice is always present in the text, by how the text is organized, how the data is presented, and what participant quotes are used or ignored.

- **Emotionality:** Alvesson and Skoldberg (2009: 244) caution that emotion plays an inevitable and important part in the motivation and choice of research orientation, and of the specific way in which a research topic is handled. The qualitative ontological exploration of the nature of reality motivated the narrative approach without acceding to ‘emotional research’ in this study, as suggested by Harvey (2006: 341). To avoid inappropriate emotionality (related to the experiences and perspectives of most of the participants), the researcher maintained neutrality by interpreting and processing personal feelings before and during the empirical and theoretical work as recommended by Alvesson and Skoldberg (2009: 245). Journaling and personal reflection proved to be effective sources for bracketing emotion and/or bias during this research process. Bracketing of personal bias is addressed further under the section of Trustworthiness.

4.7. RESEARCH DESIGN

Much ambiguity surrounds the term “design”. It can either refer to all those decisions a researcher makes in planning the study (Monette et al, 2008: 9; Babbie, 2007: 112); or, it can refer to a phase in the process (Kreuger & Neuman, 2006: 12; Bless et al, 2006: 71). Yin (2009: 32) argues that research design deals with a logical problem and not a logistical problem. Relating this to a practical analogy, before a builder can develop a work plan or order materials, they must first establish the type of building required as well as its uses and the needs of the occupants. The work plan follows from this (Blaikie, 2007: 21). In other words, when designing research, the issues of sampling, method of data generation, and design of questions are all subsidiary to the matter of ‘What evidence do I need to collect?’ to answer the research questions in a convincing way (Richards, 2005: 139).

The term 'research design' has dual connotations that can refer in the first place to the alternative logical arrangements from which one or more design can be selected (such as experimental research designs, correlations research designs, descriptive research designs and others in this category). The second connotation refers to all the decisions taken in planning the study which include the overall type or design as well as the decisions about sampling, sources and procedures for collecting data, and data analysis (Fouché et al, 2011: 143).

Descriptive research design helps provide answers to the questions of 'who, what, when, where', and 'how' associated with a particular research problem; however, a descriptive study cannot conclusively ascertain answers to the questions 'why'. The descriptive disposition of this study is found in the descriptive self-reports from the participants as well as the descriptive component during analysis and report writing (Rubin & Babbie, 2008: 80). For this study, descriptive research was used to obtain information concerning the current status of the specific phenomenon and to describe "what exists" (Creswell, 2007:199). In line with the purpose of this study, the descriptive nature of this study yielded data that may lead to important recommendations in practice. According to Given (2007: 251), the results from descriptive research are not used to discover a definitive answer, or to disprove a hypothesis, and by virtue of its nature of describing specific a phenomenon, the results cannot be replicated.

Exploratory research was effective to gain information about the experiences and perspectives of fathers of a child with DS, as very few studies have investigated this issue (Jorritsma & Jansen, 2004). Specifically, also exploring aspects related to establishing a chapter for fathers of a child with DS in South Africa. Exploratory research is not well defined and has few explicit guidelines, yet, by its nature, has the ability to change the direction of an inquiry. By addressing the what, why, how questions of this research, it provided an opportunity to define new terms and clarify existing concepts (Streb, 2010: 374). It is a very flexible way of studying children-related issues such as this.

The exploratory character of this study may be beneficial to clarify feasibility and direction for future further research in the field of DS. The researcher also applied an exploratory research approach to create awareness for the need of a chapter for fathers. Maintaining an exploratory stance, the researcher familiarized herself with research in the field to support background to this study, at the same time developing a balanced conception of the real challenges at hand, with a future view to provide added insight and an improved understanding of the experiences of fathers of children with DS.

Although a shortcoming of exploratory research is often listed as using small sample sizes unresponsive of generalizability to the population at large, this was not viewed as a weakness in this case. With regard to this study, the sample size was sufficient to answer the research questions. Also, the purpose of the study was explorative rather than attempting to generalize the findings to the population, or to make definitive conclusions about the findings (Streb, 2010: 373). Furthermore, the sample size was adequate for thematic analysis.

Creswell (2007) identifies five popular and frequently used traditions of qualitative inquiry, each representing their own disciplines and procedures, namely: phenomenology, narrative research, ethnography, grounded theory and case study. The researcher assessed the following designs as unsuited to the research topic: narrative biography (reporting the life story of an individual); ethnography (studying a social group or individuals within that group based primarily on observations over a prolonged period of time spent by the researcher in the field); and, grounded theory (developing a substantive theory that is grounded in data). The case study's strategic value lies in its ability to draw attention to what can be learned from a single case or single phenomenon within a group (Schram, 2006: 107), and was therefore not a suitable consideration to answer the research questions of this study.

The phenomenological research design aims to describe concepts and experiences as accurately as possible, refraining from any pre-given framework, but remaining true to the facts (Thomas, 2004). In general, phenomenological research is well suited for studying affective, emotional, and often intense human experiences (Merriam, 2009: 26). Although a case study design may have been an option, the decision rested primarily on suitability to the topic. Hence, because this is a study which describes the meaning of the lived experiences of a phenomenon for several individuals (Creswell, 2007: 57), it is rooted in phenomenology.

Aspects of interpretivism also feature in this design. The aim of this study rests on the understanding or 'verstehen', the researcher's interpretation of the reality, and the meaning that participants give to their world. Lichtman (2010: 80) defines this 'world' as the 'life experiences' in which we are all involved, adding that interpretation of this 'lived experience' rests on what the researcher discovers through the language of the participants (Moen, 2006: 61). Aligned with the aims of this study, the interpretivism finds significance and substance in social action to which people attach meaning. As this approach involves the opinions and experiences of people who are familiar with either

their own, or the situations of others, the researcher acknowledges variable and multiple realities resulting from interpretation and assumption (Creswell, 2014: 8; Fouché, 2005: 271).

The researcher's desire to impose meaning on the lived experiences of participants is clear in the narrative presentation of the participants' experiences in the analysis. Rather than simply report the findings, the intent was to present the participants' experiences holistically in all its complexity and richness (Moen, 2006: 60). Being of reflective nature, interpretivism requires close collaboration with participants and their situation, illuminating the reality (lived experience) of the researcher as much as that of the participants.

The researcher also included aspects of constructionism by seeking the complexity of views rather than narrow meanings slotted into simplistic groups. Hence, the researcher endeavoured to understand how fathers of children with DS construct meaning to their living world, and accordingly, to interpret what was found (Creswell, 2014: 9).

4.7.1. Research Methodology

Rajasekar, Philominathan and Chinnathambi (2013: 1) refer to research methodology as the work plan of research, thus the procedures by which researchers go about describing, explaining and envisaging specific phenomena. In answering the research questions and fulfilling the aim and objectives of this study, a number of decisions were taken of which the following were key: *How* could the researcher obtain a clearer perspective of the research problem and situate the topic in a larger knowledge pool? *Who's* experiences and viewpoints could the researcher study in order to contribute to gaining more knowledge about the research issue? *What* would be the most effective way to generate rich data to answer the research questions? The responses to these questions are provided in the section below, referring to, firstly, the literature review; secondly, sampling; followed by data generation and research instruments applied for this study.

- **Literature review**

The researcher's epistemological and ontological orientation rooted in phenomenology, informed both the literature review chapters (Feak & Swales, 2009: 13). The literature reviews aim to express certain views on the nature of the research topic, how it is investigated, and indicates the effective evaluation of documents in relation to proposed

research. The researcher adhered to the four principles of the literature review as proposed by Silverman (2012: 227-229) as follows:

- **Show respect for the literature:** Even though the current study pursues a narrow research topic, the researcher respectfully acknowledges the wider field and endeavoured to connect it to this study where significant.
- **Be focused and critical:** The researcher endeavoured to show a critical perspective on the included literature by approaching it with scepticism and questions regarding its content and inclusion for this study.
- **Avoid mere description:** The researcher carefully considered the literature included for this study and endeavoured to describe and inform rather than report.
- **Writing up the review after the other chapters:** The researcher initially wrote the literature chapters after completion of the first chapter. However, two critical disadvantages stemmed from this: thinking that these chapters are relatively easy, and, not knowing which parts of the literature is relevant to the findings until the analysis of the data was completed. This resulted in extensive revision of the second literature review chapter after analysis of the data.

The literature review of this study provides readers with answers to the following questions:

- What is already known about the topic?
- What does the researcher have to say *critically* about what is already known?
- Has anyone else done anything similar or related to what is being proposed?
- Where does this research study fit in with what has gone before?
- Why this research is worth doing in the light of what has already been done?

This study offers two literature review chapters which are organised to lead the reader naturally and coherently to the research objectives. The researcher's reporting style leans toward research prominent (or information prominent) citations. Also known as non-integral citation, the attention is focussed more on the research and less on the individual researchers involved (Lynch, 2014: 17).

An extensive body of literature was reviewed and integrated for this study as accumulated information lays the foundation of any research (Vivar, McQueen, Whyte & Armayor, 2007: 60) and contributes to a clearer understanding of the nature and meaning of the research problem (Fouché & Delpont, 2011: 134). The overall organisation of both the literature review chapters is thematic, the researcher deemed it appropriate to combine

different aspects of organising principles to follow a general-to-specific pattern as proposed by Lynch (2014: 17). A separate literature review section is dedicated to the motivation, purpose and necessity for establishing a chapter for fathers of a child with DS (See Addendum C).

The researcher followed Kreuger and Neuman's (2006: 462) guidelines as follows: As a point of departure, the researcher invested in a good research textbook. Thereafter the limits of the theme were drawn to refine the topic to ensure that only resources that pertain indirectly to the subject was collected. A file was carefully and systematically organised with thematic divisions (chronologically organised to most recent) of journal article hard copies collected over a protracted period. Electronic copies were filed similarly. The researcher located sources of literature by reviewing the general fields as well as the subject of focus. Computer databases of several universities were consulted. In this regard the researcher relied on the invaluable assistance of the subject librarian at NMMU to locate indexes, abstracts and computerised databases.

The researcher investigated, evaluated and sifted through copious sources in order to arrive at conclusions about the merits and failings of alternative ideas contained within the literature, not to criticise other researchers, but to gain a holistic picture of available literature available related to the research subject. Theoretical saturation was reached when the researcher acquired familiarity with the references cited in the most recently published articles (Rubin & Babbie, 2008: 123) and the research questions could be significantly addressed by the relevant information gathered from the literature.

The researcher heeded the caution of Bless et al (2013: 50) to not be influenced by previous research results and to not accept what has been written or explained without examining it critically. In order not to influence researcher objectivity, in this study information from literature was applied inductively (Creswell, 2014: 21).

- **Sampling**

As this investigation includes aspects of exploratory research, non-probability sampling was useful to find out whether fathers experience challenges during the diagnosis and the fathering experience in the early years of their child with DS or whether issues actually even exist. As no current research on this issue exists, the potential sampling bias of non-probability sampling exists, as cautioned by Oppong (2013: 205). In this regard, Maree (2007: 78) maintains that if a problem or issue does not exist even in a biased sample, it is

unlikely to be present in a selected relatively unbiased sample (whether using another non-probability sampling technique; or even a probability sampling technique). Guided by the aims of this research, as well as the principles of appropriateness, participants were selected who could best inform the research with regard to the theoretical requirements of the study and would be able to provide adequate data to develop full and rich description (Neuman, 2009: 204).

Participants were purposively selected based on the judgement of the researcher (Rubin & Babbie, 2008: 247), to provide reliable, meaningful and accurate information regarding the research problem (Bless et al, 2013: 177; Neuman, 2009: 203). There is little reliable guidance on the appropriate sample size needed for thematic analysis, with suggestions ranging from 6 to 400+ depending on the type of data collection and project. One approach is to continue to include data until no further themes are found; that is, until saturation (Guest, Bunce & Johnson, 2006: 63). The researcher did not consider this to be a weakness as the diversity of experiences and perspectives within the sample purposefully informed an understanding of the research problem of this study (Creswell, 2007: 125).

The researcher observed the advantages and disadvantages of purposive sampling proposed by Dudovskiy (2012) as follows:

Advantages:

- It was a cost-effective and time-effective method as all the participants could be reached electronically.
- The wide range of sampling techniques allowed the researcher to select a representative sample of fathers of children with DS from the fairly limited population of primary sources who could contribute to this study.
- Based on the purpose of the study and knowledge of the population, homogeneous sampling (based on shared characteristics of participants) was best suited to achieve the aim of this qualitative study. The homogeneity of the group depended on two factors: firstly, interpretative concerns (degree of similarity or variation that could be contained in the analysis of the phenomenon), and second, pragmatic considerations (ease or difficulty of contacting potential participants due to the relative rarity of the phenomenon). Relevant to this study, the subject matter itself defined the boundaries of the sample.

Disadvantages:

- A disadvantage of purposive sampling is its vulnerability to errors in judgement by the researcher in terms of researcher bias. However, the judgemental, subjective component of purpose sampling is only a major disadvantage when such judgements are ill-conceived or poorly considered. To alleviate this, the researcher based judgement on clear sampling criteria which links to the available literature and the theoretical framework of this study.
- The subjectivity and non-probability based nature of participant selection in purposive sampling makes it difficult to defend the representativeness of the sample. However, the phenomenological nature of the research question supports the appropriateness of judging which participants to use. It was evident from the analysis that purposive sampling was an appropriate choice for meeting the aim of this study.

Participants who could purposefully inform an understanding of the research problem of this study were selected as follows. From the population of fathers of children with DS, the researcher selected 22 fathers to participate in the study. The initial sample list included: 7 fathers selected from the database of a local informal parent support group; 9 fathers recruited from the researcher's database of families known to have children with DS; 4 fathers who were suggested by mutual friends; 2 fathers whose children attend the same special school as the researcher's daughter met at a parent meeting.

From the initial list of fathers invited to participate in the study, 11 fathers eventually committed. Fathers who declined the invitation to participate, provided the following reasons: son already a teenager and father had no clear memory of the early years due to contract work which kept him away from home for protracted periods; excessive work commitments; limited personal time to complete the responses to the interview guides; did not want to revisit "that painful time in their life"; "choose to forget that time; does not like writing down "personal stuff like that" (but also declined the option of a personal interview); was not present at birth of the child (or the diagnosis disclosure) and is currently not actively involved in the child's life; "not in their nature to discuss personal matters such as this." The preceding three responses were from black African fathers. In line with the ethical treatment of study participants, the researcher diplomatically and tactfully accepted these refusals (Strydom, 2011: 121). The researcher acknowledges and respects the sensitivity of cultural bias.

According to Sagahutu and Struthers (2014: 154), having a child with DS is often perceived as an ancestral curse amongst many of the South African ethnic cultural

groups. This leads to stigmatization of both the child and the family members, and regularly results in the children with DS being hidden from society, and commonly subjected to harsh living circumstances (Cowles, 2003:13). Furthermore, it is not uncommon for African men to leave the mother of the disabled child, and she is often blamed for the child's impairment (Christianson et al, 2002). Stigmatization is further encouraged by communities who condone such abandonment.

In urban areas men also frequently leave the mother after the birth of a disabled child, but more often as an escape from the associated pressure of caring for the child rather than the stigma associated with the birth (Lansdown, 2002: 9). The latter was the experience of a father who declined to participate in this study (this was the father who said that he was not present at the birth and is not involved with the child). He only heard afterwards that the child had DS. He did however say that he supports the child financially when it is within his means to. It stands to reason that the added issue of stress in fathers of children with DS (with particular emphasis on the problem of stigmatization and social attitudes toward their children), may negatively impact both the father's acceptance and his fathering experience of his child (Ovens, 2009: 2).

In the innovative compendium, *BABA: Men and fatherhood in South Africa*, Morrell and Richter (2006: 2) introduce this topic in rather pallid terms: "Not all fathers are proud to be fathers, and unfortunately not all fathers want to participate in the lives of their children. They seldom attend the births of their own, they don't always acknowledge that their children are their own, and they frequently fail to participate in their children's lives." Almost no literature exists on the topic of being a father in South Africa and the vast diversity within this spectrum would call for a separate research study altogether.

The written response of the father who did participate was notably deliberate and any further exploration by the researcher was repudiated. He remarked, "This may be a cultural thing and also linked to upbringing...". The researcher is grateful for his valuable contribution to this study and completely respected his privacy.

The questionnaires were distributed to every father who committed, however two of the fathers who initially agreed to participate in the study disregarded follow up attempts from the researcher, and never submitted their responses. In their defence, these fathers referred to specific personal, and familial, challenges at the time. As the DS community is a fairly small group and privacy was assured, the researcher reserves the right not to disclose the nature of these issues as it may lead to identification of the participants.

Consistent with ethical consideration of participant wishes, the researcher respected their withdrawal with sensitivity and did not make further contact.

The following biographical information pertains to the participants:

It was interesting to note that fathers of younger children were more inclined to participate in the study. The researcher ascribes this to the likelihood of the diagnosis process still clear in their minds, and also that their reality still involves complete immersion in the early years of their lifelong journey with DS. A further point of interest was that it was predominantly fathers of younger male children who participated in the study. Ages of children varied from age 2 to age 12, and 9 out of the 11 children are males.

The ages of the fathers at the birth of their child varied between 31 and 54, and the ages of fathers at the time of participating in the study varies between 37 and 63. In line with the sampling criteria, all fathers were the biological fathers of the child with DS and have been married between 6 and 33 years. Occupations of the fathers included: teaching, higher education, entrepreneur business owners (within construction as well as retail and service sectors), financial consultancy, IT, equity sales trading, and marketing and advertising. Curiously all the participants held moderate to high qualifications.

Of the participants, 8 knew the diagnosis only after the birth and 3 knew before the birth that they were expecting a child with DS. Regarding the child's position in the family, 6 children with DS are the youngest and have older siblings; 3 are the oldest and have younger siblings; and 2 are only children. Tragically one child passed away a few months before the study commenced. His father chose to honour his son posthumously by participating in the study.

- **Qualitative data generation**

Successful data gathering was largely dependent upon accessibility and the researcher's ability to maintain cooperation and a relationship with participants (Fouché & Schurink, 2011: 325). The initial contact with participants included particulars to affirm the researcher's credentials and bona fide status (Grinnell & Unrau, 2005: 236); as well as practical aspects pertaining to the research, such as data collection methods (Bailey, 2007). Given no method is superior to the other (Greeff, 2011: 341), the data generation decisions were guided by the purpose of this study with different options being explored.

Focus group interviews

The researcher acknowledges that the focus group interview is a meaningful method to explore thoughts and feelings (Greeff, 2011: 341) required in a study such as this. However, this option posed logistic obstacles regarding location, personal schedules and time constraints of participants. One-on-one interviewing is predominantly applied for data generation in qualitative research (DePoy & Gilson, 2008: 108). However, guided by the clear preference of most of the participants, the researcher followed the self-report method.

The researcher formulated specific questions related to sensitive issues, as well as questions focussed on exploring sensory perceptions, mental phenomena (thoughts, memories, associations, fantasies) and, in particular, individual interpretations as recommended by Pietkewicz and Smith (2014: 11). Because the nature of this study is also concerned with significant existential issues, the researcher remained mindful to the effect of this process on participants. None of the participants reported any significant problems during this process and no measures need to be taken (such as referral for therapy, or similar).

Based on the interview guide approach (Bless et al, 2013: 21; 218), the researcher compiled a questionnaire incorporating aspects of both the unstructured and semi-structured interview format. Unstructured: by posing open ended questions that allowed participants to clearly express their ideas about particular issues, to elaborate on ideas, and to maintain focus on the issues at hand rather than wander onto unrelated topics (Greeff, 2011: 351). Semi-structured: the researcher set predetermined open-ended questions which would guide rich information by providing a fuller picture of the participants' belief about, perceptions and experiences of being the father of a child with DS.

In comparison with a semi-structured interview, the self-report format allows participants to provide a fuller, detailed picture of their beliefs, perceptions and experiences; and, affords both the researcher and the participant more flexibility to follow up on anything emergent from the written response (Greeff, 2011: 352). Johnson and Christensen (2008: 205) note that this reflective, introspective method for systematic data generation allows for increased comprehensiveness, as clarification can immediately be sought by the researcher. Thus the researcher deemed this method most appropriate to this study.

Questionnaire/ self-reports

Consistent with the semi-structured interview format, the researcher's questionnaire presented a set of predetermined questions to engage the participant and designate the narrative terrain (Monette et al, 2008: 178). Having clarified the sensitive and personal nature of certain questions during the initial communication, the researcher was confident that the participants understood the broad range of themes covered in the questionnaire. A strategy to ensure rich and personal information was to prompt participants, during the telephone or personal conversation, about the importance of sharing and discussing their personal experiences, and the value it would add to fathers in similar situation (Callary, Rathwell & Young, 2015: 68).

The questionnaire was arranged in an appropriate and logical order to cover the topic thoroughly; jargon was simplistic to eliminate confusion; questions were open-ended to allow free expression and elaboration; and, the questions were focussed to ensure the generation of specific information required for the purpose of the study (Greeff, 2011: 352). The researcher's supervisor guided the process of refining the questionnaire. No participants indicated problems with either the questionnaire, or their written responses.

Advantages of using the self-report (Hunt & McHale, 2008: 1416-1417) for this study were: it simplified analysis procedure as the interview was already in writing and no transcription was required; it was a cost effective method; it accommodated the variety of participants who live in different areas; it was convenient for both researcher and participants in terms of personal time schedules; and, because the participants had the opportunity to complete it in their own time, at their own pace, in their own words and in their own space, it eliminated any possibility of interview anxiety for the participants.

Bless et al (2013: 193) add that participants could assess private thoughts, feelings and behaviours in own private settings; participants were provided the opportunity to report on thoughts, feelings or behaviours in a hypothetical way; and, the self-reflective nature of the questions offered the researcher participants' own, very personal accounts which provided a more accurate sense of how things affected participants in terms of their experience. Rather than accepting information from a participant that may be slanted toward what the *researcher* wants to hear (or the participant *thinks* the researcher wants to hear), the self-report allowed the participant to respond in his *own* words, in his *own* voice, with his *own* narrative and language.

Disadvantages of the self-reports include (Bless et al, 2013: 194): participants lying to make themselves look good; participants responding in a way that they think the researcher might want them to respond; participants can respond in a way that makes them appear more distressed than they actually are; and, participants may respond in a socially desirable way which they may feel is more acceptable to others. Although these are valid concerns to consider, and the researcher was vigilant to assess for this, none of the participants' behaviour or responses reflected any of the aforementioned. All the responses were examined for contextual clues and "creative" language that could point toward pretence or dishonesty. The researcher did not perceive any of the responses indicative of deceit, pretext or deflection in any way. Minimal clarification was required by the researcher, and this was done by email. The responses were attached to the original self-report.

Polkinghorne (2005: 137) cautions that translating a reflective awareness into a written or spoken expression may be compromised if participants struggle to find the right word to accurately express a feeling, thought or experience. The researcher acknowledges that in this "translation" of the emotion into either spoken or written language, to a lesser or larger degree, meaning may be lost. Multiple participants provided accounts from different perspectives, serving to deepen the understanding of the investigated experience, or phenomenon. Polkinghorne (2005: 140) suggests that this can be seen, in a sense, as obtaining a kind of triangulation of the experiences of the participants.

The nature of the research topic compelled some participants to revisit a space of discomfort and unease which, in effect, is a reflection of their experience and not necessarily just an account thereof. "Any gaze is always filtered through the lens of language, gender, social class, race, and ethnicity. Individuals are seldom able to give full explanations of their actions or intentions; all they can offer are accounts, or stories, about what they did and why..." (Denzin and Lincoln, 2008: 12).

- **Research instruments and procedure**

Telephonic interviews

Step one was the telephonic or personal interview. Once the researcher established the sample for the study, a telephonic or personal interview was held with each prospective participant during which the researcher introduced herself, explained the research, research conditions, research procedures, the selection of participants, and the expected

contribution of the research itself as suggested by Neuman (2009: 376). Issues pertaining to privacy and confidentiality were clarified.

Invitation to participate

Step two involved a written invitation. Every person on the sample list received an invitational letter, assent form, as well as the declaration (see Addendum A) which was signed as recommended by Lankshear and Knobel (2004: 110). The letter of invitation provided the necessary information regarding the study, purpose and application of the self-report questionnaire, issues of confidentiality and privacy, and explained the data generation procedure. Participants were requested to return completed consent forms at their earliest convenience.

Questionnaires

Fathers who committed in writing to participating in the study received a self-report questionnaire electronically (see Addendum B). The researcher divided the questionnaire into different sections in order to facilitate a logical flow of questions and the eventual processing of data (Delport & Roestenburg, 2011: 196). The questionnaire was kept purposely fairly short to encourage completion, and the researcher took care to phrase questions in an appropriate manner to capture the participants' subjective realities and not be influenced by biases from her prior research (Nakash, Hutton, Jorstad-Stein, Gates & Lamb, 2006).

The questionnaire was set out as follows (see Addendum B).

Section A: Basic relevant biographical information requirements;

Section B: Open-ended questions regarding the diagnosis and experiences relating to the diagnosis. This was followed by questions pertaining to support during this time.

Section C: Open-ended questions relating to possible challenges that the father has had to face, or currently face in parenting his child with DS. Participants were encouraged to include negative and positive aspects.

Section D: Participants were asked to explain how their experience of fathering a child with DS affected their emotional, physical, cognitive, behavioural and spiritual domains.

Sections E, F and G: Participants were asked to define their role as a father raising a child with DS and to elaborate on how their experience to date could have been enhanced or influenced to be more positive.

Section H: Participants were asked to respond about their perceived value in joining a forum specifically for fathers, and their opinions around what would constitute such a meaningful endeavour.

Three weeks were granted for submission of questionnaire responses. The researcher extended this period to accommodate the request of three participants. All responses, except the two who had withdrawn, were submitted within a six week period.

The researcher feels that the following is relevant in justifying the use of self-report questionnaires: Writing gives a person more time to choose the perfect words and phrasing, while speaking requires thinking on your feet. Once something has been said, there is no “delete” key. Writing allows the individual to write, stop, edit, correct, without having to deal with the other person’s reactions or interruptions or even just that “look” that speaks volumes (for example in a focus group setting). When writing, there is no guarantee that the reader will understand exactly what the writer means, but at least the writer is sure that he has said it to the best of his ability. This does not happen when speaking.

As seen in the Chapters Two and Three, fathers have specific expectations of self and roles that they slot themselves into. The most common response to disclosing the diagnosis of a child with DS is “Oh shame!” In the researcher’s experience, this societal mentality often inhibits spontaneity to talk about it. Orphan (2004: 13) refers to “other people’s discomfort”, “disapproving comments” and “loud tuts” which every parent of a child with DS can attest to and which often leads to self-imposed social exclusion. The participants of this study all have young children. “One of the most difficult issues is coming to terms with the fact that their child with a disability is not a situation they can fix...” (Orphan, 2004: 111). Seen from this perspective, it is not difficult to infer why writing was the preferred option to respond to questions related to how this position affects the participants.

Andrews, Squire and Tamboukou (2008: 48) confirm that participants are generally reluctant to participate in studies related to sensitive topics. This was clear from the number of fathers who rescinded from participating. Although a few participants responded in a straightforward manner, the majority of responses offered detailed descriptions and thorough, clear explanations of the participants’ thoughts. Three participants presented extensive, highly insightful reflections, responding to the questionnaire in essay-like manner.

- **The researcher as instrument of data generation**

“...the researcher is as much a part of the inquiry as the intent of the study and the inquiry process. In fact, the researcher’s thinking lies at the heart of the inquiry...Ill-conceived dissertation folklore...contribute(s) to “dissertation block” by diverting attention from the very wellspring of knowledge that feeds the dissertation – that is, students’ own professional experiences, personal intellectual concerns, and assumptions about knowledge” (Piantanida & Garman, 1999: 24).

Engagement with the ‘researcher as research instrument’ notion is very much dependent on the researcher’s worldview and her own ontological, epistemological and axiological underpinnings of what constitutes acceptable research. The researcher’s ontology is rooted in an empathetic better understanding of people, respecting that they are the experts on their own life, and that the process of making sense of their world is informed by their own experiences, perspectives and perceptions. In line with this, the researcher’s epistemological orientation leans toward acknowledging that knowledge arises from the understanding of that which is happening and making meaning of it, believing that, within this, those who are personally experiencing it construct knowledge through a process of self-conscious action.

The phrase researcher-as-instrument refers to the researcher as an active respondent in the research process (Turato, 2005: 510). The researcher’s facilitative interaction creates a conversational space (Owens, 2006: 1161) - that is, an arena where respondents feel safe to share stories on their experiences and life worlds. Such a space was created through well-considered open-ended questions to guide the participants to formulate their own responses (Poggenpoel & Myburg, 2003: 418). It is also the researcher who is instrumental in translating and interpreting data generated from the respondents into meaningful information (Poggenpoel & Myburg, 2003: 418). This is further supported by the researcher’s unwavering ethical transparency throughout. According to Janesick (2003: 48), “...just how explicit this position is ‘owned up to’ is also dependent on the underlying assumptions and within the social contexts of acceptable research practice within disciplines and theoretical schools of thought.” The researcher remained in close contact with the participants and was at all times available for clarification or other questions.

Certain personal aspects may pose a possible threat during the research process. These are: the researcher's mental and other discomfort could pose a threat to the truth value of

data obtained and information obtained from data analyses; the researcher not being sufficiently prepared to conduct the field research; not being able to do member checking on findings; conducting inappropriate interviews; not including demographic data in the description of the results; the researcher not being able to analyse interviews in depth; and, describing the research methodology and research results in a superficial manner.

The first point regarding emotional investment refers to the researcher being too close to the topic, or the researcher's own frame of reference and experience. The researcher has always viewed her own experience as mother of a child with DS in a very positive light. Although the researcher acknowledges that "bracketing in" (biasing in) deepened her level of empathy for families of children with DS, she has made every effort to be unbiased throughout this (and previous) studies in the field. Issues of being related to the lived world reality of the study and the participants were discussed at length with the study supervisor and objective, critical readers conducted member checks and checked data analysis independently.

4.8. DATA ANALYSIS

The purpose of data analysis is the meaningful interpretation of the generated data of a research study (Yin, 2009: 140).

Fox (2004) distinguishes the four fundamental approaches to qualitative data analysis as: Thematic analysis (TA), a generic approach to data analysis, enables data sources to be reduced to key ideas in terms of the principal concepts or themes. Historically the terms content analysis (CA), qualitative content analysis (QCA) and thematic analysis (TA) have been used interchangeably to refer to very similar approaches to qualitative data analysis (Joffe, 2011: 209) Noting that CA/QCA has taken somewhat of a backseat to 'branded' approaches to qualitative analysis (such as grounded theory and interpretative phenomenological analysis) which have developed and provided researchers with systematic procedures for analysing qualitative data, the term 'thematic analysis' is now associated with a distinctive set of procedures (Braun & Clarke, 2006: 77-101). In contrast, CA is less clearly branded and offers various versions and varieties. It can thus be assumed that CA and TA can be very similar/identical, or they can be very different, depending on how researchers make sense of, and use, both of these methods.

Interpretive phenomenological analysis (IPA) has two components. It is phenomenological, attempting to understand how participants make sense of their

experiences, but it recognises that this involves a process of interpretation by the researcher. It looks at subjective states so takes an insider perspective. IPA is interpretative, thus recognises negotiation between the researcher and the participants to produce the account of the insider's perspective, so both researcher and researched are "present". IPA is often combined with the constant comparison method and elements of content analysis (Hancock, Windridge & Ockleford, 2007).

The researcher agrees with Clapper (2014) that standardization of terms may cause confusion, however, it appears that the distinction lies in the process, rather than in the characteristics of the different analyses. Clapper (2014) argues that in qualitative research, TA and CA can be done in the same study, depending on the type of qualitative research design and the number of steps the researcher uses. Whilst CA may be more related to initial analysis and the coding process, the TA analysis may occur after the coding process as the researcher aggregates the similar codes to form major concepts or themes (Braun & Clarke, 2006: 7).

Once the researcher had all the raw data, copies were saved on hard drive, working copies were printed on which names were redacted, and responses were individually numbered for reference.

- **Thematic analysis**

Thematic analysis (TA) is a method for identifying, analysing, and reporting patterns (themes) within data. It minimally organises and describes your data set in (rich) detail (Braun & Clarke, 2006: 79; Holloway & Todres, 2003: 347). It is viewed by some as a tool used across different methods (Boyatzis, 1998; Ryan & Bernard, 2000; Holloway & Todres, 2003: 346) while others argue that it should be considered a method in its own right (Braun & Clarke, 2006: 77).

Given its theoretical freedom, TA provided a flexible and useful research tool to provide a rich and detailed account of data for this study. Whilst some methods, for example, conversation analysis (CA), interpretive phenomenological analysis (IPA), discourse analysis (DA), narrative analysis (NA) and grounded theory are wed to or stem from a particular theoretical or epistemological position (Smith & Osborn, 2003; Murray, 2003; Willig, 2003), others, such as TA, are essentially independent of theory and epistemology, and can be applied across a range of theoretical and epistemological approaches (Braun & Clarke, 2006: 77).

Considering the aim was to investigate the experiences and perspectives of fathers with a child with DS and to explore how these impact the father (intra-personally and inter-personally), the exploratory-descriptive nature of this study guided the researcher. Given that this is an under-researched area and that the researcher did not know the views of the participants on the topic, TA was a useful method for data analysis.

Braun and Clarke (2006: 78) clarify the concepts used in this section as follows:

The term **data corpus** refers to all the data material of this study (participant self-reports, journal articles, websites, and so forth). **Data set** refers to a combination of, or all the individual data items within the data corpus. This means that it can be identified by a particular topic in the data, for example “grief”, in which case the data set consists of all instances across the data corpus that is relevant to grief. **Data item** refers to each individual piece of data collected, and refers mostly to the individual participant self-responses. **Data extract** refers to an individual chunk of data, taken from throughout the entire data set, which features in the final analysis. A **theme** represents a level of patterned response or meaning from the data sometimes more than the research question. The themes eventually provide an accurate understanding of the “big picture” (Saldana, 2009: 12).

A **code** refers to a particular piece of the data that contribute to a theme. An example from this study: “fear” is a code, but “fear of the unknown” is a theme. **Coding** is the primary process for developing themes within the raw data by recognizing important moments in the data and encoding it prior to interpretation (Guest, 2012: 13).

TA can be a method for reflecting reality and to unpick the surface of “reality” in the following ways. As a realist or **essentialist method**, it can report experiences, meanings and the reality of participants. As a **constructionist method**, it can examine the ways in which events, realities, meanings, experiences are the effects of a range of discourses operating within society. As a **contextualist method**, it can examine the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of “reality” (Braun & Clarke, 2006).

In TA, **themes or patterns** can be identified in one of two ways: **inductively** or **deductively**. In an inductive approach, the themes identified are strongly linked to the data because assumptions are data-driven and the coding process does not try to fit the data into a pre-existing model (Boyatzis, 1998). In contrast, a deductive approach to TA is

theory-driven, less descriptive, and provides a detailed analysis of some aspect of the data (Braun & Clarke, 2006: 102). The choice between inductive and deductive also maps onto how and why the data is being coded. Coding for a specific research question, maps onto the deductive approach. Data coding for this study followed an **inductive** approach as the researcher read and re-read the data for themes without considering themes that previous research on the topic identified (Saldana, 2009: 13).

In TA, themes are identified at either a **semantic** or a **latent level** (Boyatzis, 1998). On a semantic level, themes are identified within surface meanings of data, thus the researcher is not interested in anything beyond what a participant has written or said. Going beyond the semantic content of the data, in this study, the researcher used a **latent approach** to identify the underlying assumptions, ideas and conceptualisations. Interpretive work is involved in the development of themes for latent thematic analysis, and the analysis that is produced is not just description, but is already theorised (Braun & Clarke, 2006: 13). In line with the researcher's constructionist ontology of subjective reality, the analysis presented a rich thematic description of the entire data set to provide the reader with a sense of the predominant themes, yet did not compromise on providing insight into the depth and complexity of this phenomenon. Relevant to this study, TA is also related to phenomenology in its focus on subjective human experience. In line with the aim of this study, this approach emphasizes the participants' perceptions, feelings and experiences as focal. Rooted in humanistic psychology, phenomenology notes giving voice to the "other" as a key component in qualitative research in general. For this study, by means of self-report, participants reflected on the topic in their own words (Guest, 2012: 11).

The following six phases were followed during data analysis (Braun & Clarke, 2006).

Phase 1: Becoming familiar with the data

The researcher actively read and re-read the data to become familiar and comfortable with it, already searching for meanings and patterns. Reading through the entire data set shaped the researcher's ideas and identification of possible patterns before coding started. This included considering a large amount of literature read before as well as the eleven self-reports from participants. While becoming familiar with the material, the researcher constantly kept notes of own thoughts, ideas about what was in the data, interesting observations, and potential codes (Braun & Clarke, 2006: 93).

Phase 2: Generating initial codes

This phase involved the production of initial codes from the data. The researcher scrutinized every data item and wrote codes in the left margin of every text. Anything that appeared interesting was marked with highlighters which made it easy to recognise patterns across the data set. Initially the researcher made use of ATLAS.ti software for this segment of coding, however she preferred the manual way and found it more interesting to connect with the data hands-on by working directly on the hard copies. As there were only eleven data items, it was manageable to work through the entire data set systematically, giving full and equal attention to each one. As each data item was numbered, it was easier to use a mind-map technique and reference with data item number and question number next to codes. This also assisted the researcher to retain the context. Some extracts of data were coded for many different “themes” as relevant. Contradictions within a data item were also marked separately. Throughout this process the coding was data-driven.

Phase 3: Searching for themes

This phase started once all the data was initially coded. At this stage the researcher had a long list of identified codes. In this phase, the codes were sorted into potential themes. The researcher used another mind-map to create a large visual layout to sort, analyse, and consider how different codes could combine to form overarching themes. At this stage the researcher started to think about the relationship between codes, between themes, and different levels of themes. Some codes went to main themes and some to sub-themes. There were a few that did not belong, and those were parked under “possible”, and a few were discarded. At this point the researcher had a collection of candidate themes and sub-themes which were all linked to marked extracts of data or colour indicators. At the end of this stage, the researcher had a sense of the significance of individual themes.

Phase 4: Reviewing themes

This phase involved two levels of reviewing and refining the themes. Level one involved reviewing at the coded level. All the corresponding coded extracts were read for each theme to consider if they appeared to form a coherent pattern. If a coherent pattern was not apparent, the extract was moved to a better fit within an already-existing theme. At this stage some of the candidate themes collapsed into each other when two apparently separate themes actually formed one theme. The researcher looked for meaningful coherence of data within the themes and was attentive to clear and identifiable distinctions between themes. The researcher now had a visual thematic map and, at level two, started

to consider the validity of the individual themes in relation to the entire data set. The researcher critically reviewed the candidate thematic map against the systems theory model to evaluate whether it was an accurate representation at this stage. This check also prevented the researcher from rearranging and unnecessary refinement. At the end of this phase the researcher had a good idea of what the different themes were, how they fitted together and the overall story they told about the data.

Phase 5: Defining and naming themes

This phase involved refining and defining the themes and the researcher now had to identify the “essence” of each individual theme as well as the themes overall. At this point each theme was identified, corresponding data ordered, and organised into a coherent and internally consistent account, with accompanying narrative which was not just paraphrased content but identified what was interesting about it and why.

For each individual theme, the researcher conducted and wrote a detailed analysis. The “story” of each theme also needed to fit into the broader “story” about the data, in relation to the research question(s). To avoid too much of an overlap, each theme was considered in relation to the others. At this stage the researcher also had to identify whether a theme contained any sub-themes. These are particularly useful for providing structure to a large or complex theme, and for demonstrating the hierarchy of meaning within the data. At the end of this phase the researcher was in a position to clearly define the themes, what they were, and what they were not. A test for this was to see if the scope and content of each theme could be described in a couple of sentences. Although the themes now had working titles, they had to be named for the final analysis. Names needed to be concise and immediately provide a sense of the theme.

Theme 6: Producing the report

This phase began when the researcher had a set of fully worked-out themes. Writing up the thematic analysis is essentially telling the complicated story of the data in a way which convinces the reader of the merit and validity of the analysis. To this end it needed to be concise, coherent, logical, non-repetitive and interesting (including data extracts) within and across themes. Using particularly vivid and identifiable examples captured the essence of a point without unnecessary complexity. Extracts needed to be embedded within an analytic narrative that illustrates the story about the data, but also needed to go beyond description of the data to make an argument in relation to the research question. Where relevant, the researcher broadened out the analysis, moving from a descriptive to an interpretative level (often relating her claims to existing literature).

4.9. MEASURES OF TRUSTWORTHINESS

Because of the focus on the human component, qualitative research takes into account subjectivity in data analysis and interpretation (Lichtman, 2010: 7-8).

- **Bracketing**

It is generally understood that researchers have motives and biases based on their own biographies and contextual experiences. Bracketing allows the researcher to set aside own experiences and take a fresh perspective (Fontana & Frey, 2005). To this end, the assumptions and implications of the researcher must be clear and explicit when interpreting data (Callary et al, 2015: 66). However, Allen-Collinson (2009: 286) notes that it is impossible to bracket one's biases completely, although the process allows researchers to suspend their assumptions and "adopt a more self-critical and reflective approach in research."

As TA includes an interpretive element, the researcher did not want to suspend her biases from the research (referred to as bracketing *out* biases). Rather, the researcher wanted to understand how her own taken-for-granted assumptions about the topic might inform her approach to the entire process (referred to as bracketing *in* biases)(Callary et al, 2015: 66).

Recommended by Moon (2006), the researcher reflected on the following questions: what are my beliefs about fathers' experiences of having a child with DS? How has my own experience shaped these beliefs? What are my beliefs about how fathers perceive their experience of raising a child with DS? After thorough reflection, the researcher penned her thoughts and discussed these reflections with the supervisor, thus deepening her reflection on the topic of the study. By bracketing experiences, the researcher showcased potential biases that may shape her interpretation of the data, but at the same time, the researcher was also able to bracket *in* how her experiences might enrich the interpretations. Callary et al (2015: 67) recommend this bracketing exercise as an essential tool used in multiple stages of a research project.

Bracketing has been widely and diversely defined and described. Polkinghorne (2005: 140) describes it as a two-fold process in which free variation leads the researcher to a description of the invariant or essential structures of the phenomena, without which it would not exist. Then the use of intentional analysis focuses on the concrete experience

itself and describes how the particular experience is constructed. Bracketing is also described as identifying one's presuppositions about the nature of the phenomena and then attempting to set them aside to see the phenomena as it really is. This is to show the purely immanent character of conscious experience by means of careful description (Laverty, 2003: 23).

The expanded notation of Chan, Fien and Chen (2013: 7) offers researchers a succinct summary of four strategies for achieving bracketing:

- B**egin with a mentality assessment of your (researchers') personality;
- R**eflexivity helps you (the researcher) to identify areas of potential bias;
- A**nalyse data in according to the chosen method;
- C**omply with the prevailing gate-keeping policy when deciding the scope of the literature review;
- K**eep a reflexive diary will help to awaken your (the researchers') own pre- conceptions;
- E**ngage participants in bracketing during the data collection process when indicated;
- T**horough research planning before data collection;
- I**nterview the participants using open-ended questions;
- adopt a **N**ot-knowing stand to maintain the curiosity in the participants;
- G**enerate knowledge from participants via chosen method.

Finally, it is true that no one in the world has better knowledge than participants themselves regarding their lived experiences and perceptions. All the measures adopted by the researchers, including bracketing, aim to ensure that the findings are as close to what the participants mean as possible and in a more realistic and practical sense. It is up to the researcher to commit to the issue of bracketing and to decide how much influence there can be by the researcher throughout the research process. This indicates that there is a need to call for innovative means of carrying out qualitative research that can address the problems of validity (Chan et al 2013: 7).

- **Validity, reliability, dependability, credibility, transferability, confirmability**

Trustworthiness essentially refers to the authenticity, honesty, validity and reliability of the investigation undertaken in research. Creswell (2014: 201) differentiates between qualitative validity and qualitative reliability as follows: To ensure **qualitative validity**, the researcher employs certain procedures to affirm the accuracy of the findings; while

qualitative reliability indicates consistency of the researcher's approach across different researchers and different projects.

To increase the validity of this study, the following measures were implemented to prevent any personal bias interfering with the process of analysis and interpretation in this study. Participants provided data by means of written self-reports, which prevented manipulation or misrepresentation of data. The researcher went back to participants to check that their contributions had been interpreted correctly. Validation of coding was done in two of the phases by independent coders.

Given coding is an active and reflexive process that inevitably and inescapably bears the mark of the researcher, which, in terms of issues of **validity and reliability** supports the fluidity and creative way in which the researcher discovered the themes and patterns (Welsh, 2002: 567), the researcher preferred to continue the coding process manually after starting off the initial coding using software. Despite the notion that there is no "accurate" way to code data, which, according to Joffe (2011: 209), diminishes the logic behind multi-independent coders, the researcher employed a peer check by means of two independent graduates, familiar with research methods, to validate her own coding in two of the phases. This validation was done in the early stages of analysis. Not only was validation beneficial for the data at the first level of themes, but it also provided accurate and reliable ones for the second level. Furthermore, it made the data at the second level of themes less prone to errors and mistakes. This could be noticed at the second level of the theme codes, as the agreed codes of the independent reviewer were more consensual and there were fewer differences between them.

This happened as follows. The first one was conducted in phase three to validate the potential themes, and the second one in phase four for theme reviewing. After providing background about the study aims and research questions, each individual was provided with the same three data items with the instruction to code and organise thematically according to the data presented; in other words, consistent with the method (Richards, 2005: 139). Thus, it simultaneously served as a type of triangulation method. According to the researcher's confidentiality agreement with participants, all personal information on the data items was redacted beforehand. The results were discussed individually, differences were discussed, compared and mutual agreement was obtained. Resulting from the phase four check, the researcher defined (imploded) one theme that was not well-defined and overlapping with others.

An important step in TA is the evaluation of themes to ensure they represent the whole of the text, which is why the researcher involved outside reviewers to help with validating themes in the early (and later) stages of data analysis. Primarily, this was to test if the themes the researcher identified were compatible with the whole of the text or not. However, the main purpose of this procedure was to “build reliability in thematic analysis coding” (Hosmer, 2008: 52). As a result, the researcher was also now better informed of any conflicting results with respect to the themes that were added or removed by the one independent reviewer (Hosmer, 2008: 52).

According to Hosmer (2008: 52), including two outside/independent reviewers at two separate phases could “probably” build a strong process for analytical credibility “similar to reliability from a positivistic perspective.” However, Guest (2012: 17) argues that especially in analysis revolving multiple analysts, reliability can be a concern due to wide variety of interpretations from multiple researchers.

The researcher acknowledges that utilising different display techniques may have clarified descriptions and simultaneously increased the overall reliability of the research to make it valid for other researchers. However, the researcher presented different quotations (participant verbatim responses) to provide evidence, support and validate interpretations (Joffe, 2011: 208).

A constructivist approach to the analysis relied on analyses of the data without engaging pre-existing themes, which means that it can be adapted to any research that relies only on participants’ clarifications. In other words, each statement or idea contributed towards understanding the issues, which led to an appreciation of the whole picture. Thus, every statement was valid in understanding a single concept or ones shared with other statements. In this way, concepts were constructed to give a full picture of the views and actions of the participants. Furthermore, presenting similarities and differences between the participants’ perspectives may also assist the readers to obtain a global view (Blacker, 2009).

Within the qualitative research paradigm, external validity is replaced by the concept of transferability. Transferability is the ability of research results to transfer to situations with similar parameters, populations and characteristics (Marcellesi, 2015: 1308). As the researcher believes in the subjectivity of individual experience, transferability of results of this study is highly unlikely. However, based on previous research, the researcher does acknowledge that there may be correspondences and similarities.

Dependability is a concept similar to, but not the same as, reliability (Bless et al, 2013: 237) and implies accuracy and consistency in the findings of a study as well as adherence to procedures and methods of sound research practices as provided throughout this study. Detailed description of how data was generated, recorded, coded and analysed supported by good examples, suggests to the reader that the results are dependable and trustworthy (Denzin & Lincoln, 2008: 186). Finally, the researcher's supervisor followed the progress of the research study and offered critical evaluation throughout the entire research study. This consistency check was maintained throughout to assess the trustworthiness of the study and to harness and restore unintentional bias by the researcher. This checking system also served as continuous control in terms of meeting the research objectives.

Credibility corresponds with the concept of internal validity or *truth value* which describes the accuracy of how the reality of the participant is depicted and whether this truly reflects the aim of the research. Validity therefore questions the truth and correctness of the researcher's engagement with the research in order to provide an equitable perspective of the data analysis and interpretation (Bless et al, 2013: 236). Truth and credibility was also ensured by additional strategies (Creswell, 2014: 201). Triangulation between the data (participants), literature and immersed researcher involvement created a meaningful rationale for themes in the process described above. The use of thick, rich description in findings added an element of shared experience to the discussion and multiple perspectives about a theme provided a richer and more realistic view. To add credibility, the researcher also included discrepant or negative information as an accurate and realistic depiction of real life. Clarification of bias, explained in Chapter One, created an honest and open narrative that resonates well with readers.

Transferability is closely related to external validity, referring to the degree to which the research findings can be applied to similar contexts. Hence, it is also referred to as *applicability*. The researcher provided detailed accounts of the context in which the data was generated, about the researcher as a person as well as her relationship with the participants. This allows comparison and assessment by others of the similarities between the researcher's situation and other contexts. Generally, a correspondence between understanding the context from where findings emerged and other contexts can be imagined where such findings might be meaningful, a study is deemed to having high transferability (Bless et al, 2013: 237). Internal generalisability relates to individuals or groups with special or unique attributes, and although interpretations and observations of the researcher are clarified by the specific contexts in which they occur, findings may not

necessarily be generalised, however it can be applied or be relevant to other similar situations (Bless et al, 2013: 238). To this end, purposive sampling was employed with very specific participant criteria.

Confirmability refers to the ability of other researchers to replicate the study and to obtain similar findings if they follow a similar research process in a similar context. This requires a critical evaluation of methodology. The concept of confirmability is viewed diversely by different researchers. According to Bless et al (2013: 237), confirmability allows for new studies to repeat, elaborate, challenge and even defeat old studies. This contrasts with the view of Cohen et al (2007: 134), who suggest that confirmability refers to the degree to which the research findings are indeed the product of the focus of the study and of the participants, rather than the product of subjectivity, sentimentality or perception of the researcher, which may pose a challenge when the research involves the world the researcher is a part of. In terms of a confirmability audit, the researcher kept impeccable records of raw data, data analysis, and reflective notes in an effort to ensure neutrality.

Throughout this study, the researcher aspired to maintain empathetic neutrality, or objectivity. Empathetic neutrality comes into play when the researcher is able to show empathy to the participants and the entire spectrum of the study, yet can simultaneously employ neutrality when dealing with the findings of the research. Positioning herself ontologically and as research instrument, the researcher endeavoured to remain neutral, unbiased, non-judgemental and unprejudiced throughout (Neuman, 2009: 376). Alongside every effort to 'bracket' personal opinions, perceptions and views about both the topic at hand, the participants, as well as their experiences, perceptions and views, the researcher constantly redeployed her attention to the scientific objective of the research. The researcher's long-time active involvement in the field of DS and with families of children diagnosed with DS, sustained her commitment to remain immersed in the study, yet maintain an emotional objectivity from the participants and their stories.

4.10. CONCLUSION

This chapter provided detailed clarification of the approach, design and methodology followed for this study. The investigative processes carried out in this qualitative study facilitated a better understanding of the phenomenon.

Essentially this chapter covers the two general rules that guide research design for validity in qualitative research, namely: being attentive to the fit of question, data and method; and, ensuring that each step in the analysis is accounted for (Chan et al, 2013: 3). As an integral part of this study, Chapter Four serves as prime log for the journey of this research by, as pointed out in the introduction, providing a trustworthy explication of the research plan and how it was executed.

The following chapter, Chapter Five, comprises of an exposition of findings pertaining to the objectives which underpin this research.

CHAPTER FIVE

ANALYSIS, INTERPRETATION AND DISCUSSION OF FINDINGS

5.1. INTRODUCTION

The following two chapters will present the reader with the meaning-making component of this study, and thus provide the textual bridge between what was found in the field work and the conclusions that were drawn from that evidence (Trafford & Leshem, 2012: 128).

The present study was designed to explore the perspectives of South African fathers of a child with DS. The secondary research objectives aimed to ascertain influential factors which shape perspectives, perceptions and experiences of such fathers; to determine how fathers delineate the effect of these factors on their internal and external systems of functioning; and, linking with this, whether fathers consider a purposeful support initiative as beneficial to this unique fathering experience. Interpreted and validated in the light of relevant literature, the qualitative results of this exploration will be provided in this chapter.

The population for this study included South African fathers of a child with DS; which comprised fathers of any age, income, culture or ethnic group; who either have, or have not; and are, or are not experiencing challenges in their experiences, perspectives or perceptions with regard to the fathering of their child of any age or gender with DS. The purposive sampling pre-selection criteria for participants best suited to this research study, were: South African married biological fathers of a child with DS. Fathers provided data by means of self-report questionnaires which offered them the opportunity to reflectively write about their experiences in their own words. Thematic analysis was used to derive a meaningful interpretation of the generated data.

Eleven South African married biological fathers of children with DS were recruited to participate. These participants were extracted from the database of an informal support group and from families known to the researcher. A number of participants were also recommended by other parents. The age of the fathers varied from thirties to fifties, and the children between two and twelve years. The diagnosis was known before birth to three fathers, while eight fathers only found out about their child's diagnosis after the birth. Regarding position in the family: six of the children with DS are the youngest and have older siblings; three are the eldest and have younger siblings; and, two are the only

children of their parents. None of the children have additional comorbid conditions apart from the diagnosis of DS.

Understandably, different cultures interpret fatherhood in different ways. African fathers appeared to be reluctant to participate in the study, and only one father out of the three extended invitations participated in the end. This was unfortunate as larger representation may have provided a broader diverse perspective of fathers of children with DS in South Africa. Most African ethno-cultural practices are based on values and philosophies that conflict with Western values (Kuse, 1997:21). Such values are inherent in the traditional patriarchal family system, the philosophy of keeping family matters within the family (secrecy), and the traditional beliefs in ancestral powers and witchcraft (Thabede, 2008: 239). The secrecy aspect was evident in the reaction of a father, a prominent attorney in Gauteng, who declined to participate under the pretext that, "Telling someone you hardly know all about your life is like stripping yourself naked in front of a stranger." The researcher respected his point of view and did not try to dissuade him.

Throughout this chapter, authentic participant contributions will be indicated verbatim in italicized text. The interpretation and analysis relied heavily on the narratives as reflected by the interpretations of the participants as they made sense of this life event by expressing their experiences, inner feelings, beliefs, hopes, perceptions and attitudes. Throughout this study the researcher found the participants' level of honesty reassuring, and it was both interesting and compelling to note the distinctiveness in the interpretation of their experiences. Whilst a few fathers offered reserved responses, at least nine out of eleven were completely spontaneous and candid about their perceptions and experiences. The direct quotations will be used to provide the information given by the participants as truthfully as possible, without any editing by the researcher.

Furthermore, interpretation was aided by a thorough literature study and supportive relevant knowledge extrapolated from several national and international conferences and seminars attended and from numerous conversations and mentoring sessions with parents of children with DS. This discussion is defined and limited to the written responses of the participants. At the center of this interpretation was the systems theory, which infers that all subsystems are interrelated and interdependent. Hence, the systemic link was drawn between the effect of this non-normative life event and the experience of the father. The symbiotic relationship between the internal domains and the external social systems were presented in Figure 1.1.

In line with a constructivist approach, the researcher's interaction with the data facilitated the following four broad themes to develop from the analysis:

- THEME ONE: Intra-personal experience of this life event
- THEME TWO: Inter-personal experiences of the father
- THEME THREE: Collective experience of DS
- THEME FOUR: Managing the life event

To facilitate the discussion of these themes, data were divided into themes, sub-themes and critical aspects, which all form elements of the holistic picture rather than be viewed as separate entities. Table 5.1 provides a structured overview of the findings.

TABLE 5.1: Summary of themes, sub-themes and critical aspects

THEME 1:	SUB-THEME	CRITICAL ASPECTS
5.2.1 Intra-personal experience of this life event	5.2.1.1 Intra-personal dynamics related to diagnosis: <ul style="list-style-type: none"> • Emotional subsystem • Physical subsystem • Cognitive subsystem • Behavioural subsystem • Spiritual subsystem 	<ul style="list-style-type: none"> • Diagnosis distress • Denial and guilt • Anger • Bracing for disability • Ignorance about DS • A change in plans • Acceptance
	5.2.1.2 Life span dynamics of intra-personal functioning <ul style="list-style-type: none"> • Emotional subsystem • Physical subsystem • Cognitive subsystem 	<ul style="list-style-type: none"> • Fear related to the future of the child • Expressing feelings • Realization of difference • Love, pride and inspiration • Physical demands • Post-traumatic stress • Self-criticism • Recognition of positive influence

	<ul style="list-style-type: none"> • Behavioural subsystem • Spiritual subsystem 	<ul style="list-style-type: none"> • Paradigm shift • Improved emotional state • Embracing the difference
THEME 2: 5.2.2 Inter-personal experiences of the father	5.2.2.1 Relationship to self 5.2.2.2 Spousal relationship 5.2.2.3 Father's relationship to siblings 5.2.2.4 Father's relationship to friends 5.2.2.5 Father's relationship to family	<ul style="list-style-type: none"> • Ruptured sense of self • Shift in expectation • Emotional understanding • Limited time • Enhanced relationship • Empathy • Equal attention • Gratitude and balance • Observing positive relationship between siblings • Unmet expectations of friendship • Appreciation of supportive friendships • Development of unexpected friendships • Social disconnect
THEME 3: 5.2.3 Collective experience of DS	5.2.3.1 Experience of support 5.2.3.2 Community reaction	<ul style="list-style-type: none"> • Support from parents of children with DS • Support from wife • Medical fraternity • Educational institutions • Support groups
THEME 4: 5.2.4 Managing the life event	5.2.4.1 Parenting experience of his child with DS 5.2.4.2 Role as father of a child with DS 5.2.4.3 Moving forward: supporting other fathers	

5.2. GENERAL OVERVIEW OF RESULTS

In summary, results of this study were consistent with those of Skotko et al (2011) related to parental stress, marital strain and personal outcomes; every participant reported a more positive outlook on life in terms of lessons learned, and an increased awareness of self-growth after having a child with DS. However, only a small number of participants commented on negative lessons learned in terms of unmet expectations of support (friends, family and community). A common view amongst fathers pertained to the positive impact of a mutually supportive relationship between husband and wife, as well as the overall value of support.

It appeared that fathers mostly navigated their way through the available information about DS on the internet, while others relied on their wives to source information, and two fathers gained most of their initial information from other families with a child with DS. In their accounts of the events surrounding the diagnosis of their child, four out of the eleven fathers found their interaction with medical practitioners objectionable, while the others leaned on the support provided by practitioners. The overall response from fathers indicated a deepened realization of fatherhood which extended to an increased appreciation for their typically developing child.

The notable thread throughout the responses added force to the researcher's argument that fathers may indeed benefit from the understanding and support, which, as indicated by participants, is often only accurately provided by parents who have been in the same position.

... you want someone who is walking this road as well...

... I would have liked to speak to reasonable, empathetic people who had been through something similar...experienced individuals...a kind and caring contact to share their experiences.

Central to the entire exploration of the perspectives of a father of a child with DS, is the father's intra-personal experience of this life event.

5.2.1. THEME ONE: INTRA-PERSONAL EXPERIENCE OF THIS LIFE EVENT

From participants' narratives, it became clear that being the father of a child with DS was not only a life *event*, but rather a life-*changing* event, which bears ironic correspondence to the syndrome itself. Just as the incidence of DS happens at the *moment* of conception,

so too, is the father's life irrevocably changed at the very *moment* of the diagnosis. Similarly, just as additional genetic material is added to chromosome 21, so too, the father, henceforth, experiences additional encumbrance manifesting in his emotional, physical, behavioural, cognitive and spiritual subsystems. Best likened to a kaleidoscope effect, the father's psychological landscape at the time of diagnosis was impacted by shifts and transferrals between the intra-psychic domains (subsystems), which inevitably affected the coherent whole of the father (Sawyer, 2005: 96).

Subsystems will be seceded for the purpose of the discussion. The narratives showed how each individual domain, more than one, or the entire group of internal subsystems responded to external social systems. To consider the gestalt of participants, the themes formed a cohesive flow starting at the diagnosis of their child and led to the present moment. The researcher acknowledges that, as this life (changing) event affects individuals in a highly individual way, the present is also perceived differently by each individual. Although the psychology of gestalt is beyond the scope of this thesis, it is relevant in referring to something that is made of many parts and yet is somehow more than, or different from, the combination of its parts (Merriam-Webster, 2016). This refers to the father (system) being made up of different subsystems as explained earlier; with this life event influencing one subsystem, and causing shifts in other subsystems.

Theme One provided insight into the intra-personal perplexity of how this life event impacted the domains of the father, not only related to the diagnosis, but also the life span dynamics. It furthermore showed how the domains impact each other, how this impacted the father's internal functioning, and, how his outward expression was driven by this internal manifestation. Each aspect discussed in Theme One influenced the perceptions, perspectives and experiences of the father, and provided insight into how South African fathers delineate the intra- and inter-personal effect of this unique fathering experience. These findings were corroborated by Skotko et al (2011) and Takataya et al (2016) with regard to diagnosis distress, bracing for disability, ignorance about the syndrome, and also manifestation of grief. The intra-personal dynamics related to the diagnosis and the life-span dynamics of the intra-personal functioning will be discussed in relation to the subsystem that is primarily influenced.

5.2.1.1 Intra-personal dynamics related to the diagnosis

Critical to any examination of the diagnosis is the realization that it is an intensely individual experience; as is the process of grief (Dowling et al, 2004: 1). The emotional

turmoil reported by fathers matched those observed in earlier studies (Takataya et al, 2016; Van Riper, 2007; Singer, 2006). Many similarities were noted between the emotional reaction of fathers and the general stages of grief: these being shock, denial, anxiety, anger and guilt, and eventual acceptance (See Chapter 3). Despite the stages of grief usually focussing on grief occurring after death, it is known to also occur in response to a profound loss, such as having a child diagnosed with a chromosome abnormality like DS (Dowling et al, 2004).

- **Emotional subsystem**

The overall participant response indicated the diagnosis of their child as a time of severe emotional turmoil. It is likened to grief which does not refer to a physical loss, but flows from the father's loss of dreams, ideas, hopes and expectations of the child and their life-journey together (Dowling et al, 2004: 1). Essentially, fathers perceived this as both a loss of 'what might have been', and a destruction of 'what could have been' as illustrated in the comments below.

...the dreams and prospects of raising a regular boy were destroyed.

...I felt that Down syndrome had come and destroyed our family...

Diagnosis distress

The disclosure of a diagnosis is a difficult time, albeit before or after the birth of the child. Fathers described their **shocked** reaction to a pre-natal diagnosis as **uncertainty, fear, worry and bewilderment**, which was compounded by the difficult 'waiting period' until such diagnosis was unequivocally confirmed.

At 20 weeks it was confirmed that our baby had Down syndrome...we were overcome with total fear, uncertainty and bewilderment.

...absolute shock in terms of not knowing what to expect in the least...

...worried for the health of the child...

To add to their distress, two of the four fathers who knew the diagnosis beforehand, were encouraged by their doctors to consider abortions. However, guided by personal spiritual and religious conviction, they decided against such unsolicited advice. They commented:

...accepted that it was God's will... decided to keep the baby.

...traumatic getting advice to terminate the pregnancy... the Lord Jesus Christ was nearer to us than He had ever been... we didn't want to lose our baby...

Accounting the events surrounding the delivery of a post-natal diagnosis, fathers recalled the experience as surreal. Typical of post-traumatic stress (PTS) symptoms this time is typically characterised by reactions of shock including **stunned** feelings, **numbness** and **disconnection from the reality** of their situation as follows:

It felt unreal... shocked... since this was so unexpected.

My feelings at the time were surreal, like it wasn't really happening...

...I thought that I was dreaming and that I would soon wake up and find this not to be true.

I went completely numb and felt ice cold. It felt completely unreal...as if the entire world had just stopped moving completely.

Although these findings cannot be extrapolated to all participants of this study, many fathers confirmed that their immediate concern after the diagnosis related to the health and well-being of the mother and the new-born child (MacDonald & Hastings, 2010a). Typical to the problem solver role, fathers' concern extend to their family; and the emotional needs of others appeared to supersede their own at this time (MacDonald & Hastings, 2010a: 488). Participants stated:

I cried more knowing that he was in ICU than because he was a DS baby.

... sit at his cot and pray for him for hours...what if he had serious health problems?

I had to be strong for my wife and step son.

...worried about how my wife is going to deal with the situation...I anticipated that she would be devastated. Would she be able to handle having a child with special needs? Was she going to reject the child? Was she going to run away?

Denial and guilt

Takataya et al (2016: 2) argue that because DS is an incurable condition, it holds a negative connotation for most parents. The inconceivability of such diagnosis caused many fathers to deny the reality of their situation at that time. Dowling et al (2004: 39) maintains that in its simplest form, denial is an attempt to put distance between our experience and ourselves. Hence, fathers experienced feelings which severely conflict with the usual reaction to the birth of a child. Dowling et al (2004: 31) describes denial as

a weapon with many triggers. For some fathers, denial arose from feelings of guilt about supposed wrongdoing. Denial was evident in the disbelief expressed by fathers as follows:

...Why us? Was it because we had made mistakes in the past?

...Why us? Was this a punishment for our sins?

..I felt guilty... I thought people would judge me...

Denial can be seen as the internal refusal of the father to believe what is happening at that time (Orphan, 2004: 99). According to Naseef (2001: 40), in a way denial buys the father time to discover the inner strength to handle a situation. In reviewing the literature, no evidence was found to equal the level of blunt truthfulness displayed by participants of this study to express their raw direct denial of the diagnosis. One father's expressions and actions anchored in disbelief and he wanted more than anything for life to go on as if nothing had changed, despite glaring evidence to the contrary. He said: *I remember thinking that if he died in NICU I would be sad and I would mourn him, but then at least we could go back to who we were as a family...*

Strong reactions of denial expressed by some participants included the need to "fix" the child, thereby reframing the 'story' of their reality. They commented:

...wanted to "fix" him with therapy and make him "normal"...

I wanted him to either somehow "disappear" or miraculously be "cured".

In accord with recent studies indicating typical denial responses (Takataya et al, 2016), one participant's response was marked by downplaying the effect of the syndrome; indicating his reluctance to acknowledge the diagnosis.

Our child is not severely affected by DS...

Having no frame of reference of DS, another participant's denial was evident in his refusal to acknowledge the physical evidence of the prognosis.

I was sure that his diagnosis was incorrect as I had seen her and she looked perfectly normal to me.

Kahane and Cavender (2006: 132) refer to this phenomenon as a level of self-deception that provides important survival benefits for the father: it reduces anxiety or stress and gives him a greater decision-making ability regarding the reality of his situation. For one participant who had to wait a week for the definitive diagnostic results, denial persisted

until the tests were confirmed. This father's statement indicated his denial on more than one level:

It ever really looked like he had DS... so there was a "disbelief" that remained...only once the doctor said that the tests came back positive for Trisomy 21 did I really start to accept that we had a child with DS.

Anger

Dowling et al (2004: 47) reminds us that anger is one of humanity's strongest and most powerful emotions, generally arising primarily out of anxiety. Similar to denial, it is a natural and automatic response that, in the short term, offers protection from emotional trauma. Speaking directly to the protector role, many fathers felt powerless to protect their child (and their family) from the diagnosis. Feelings of **anxiousness, helplessness, and overwhelming** most likely affected the emotional subsystem of the father. Understandably such feelings were fuelled by defenceless anger (and vice versa) about a situation that was completely out of their control. Participants commented:

I felt despondent... could not control what was happening...I wanted to surrender/give up...

I was overwhelmed by all the emotions at the same time...shock, surprise, disbelief, fear, anger...

...helpless...not knowing what to expect in the least by having a DS baby/child.

...felt helpless and completely overwhelmed...

Other responses were reflective of participants' **rage against the universe**. By asking "why?", (an aspect of denial), fathers were trying to process an event that simply made no sense to them at the time. The comments below illustrate participants' anger and discouragement:

...why me?...

Angry at God... how could He let this happen when I had prayed for a healthy child?

We went to see a fertility specialist before...been trying for a year...I was now filled with enormous regret and anger that we hadn't just given up trying for another child.

... incredibly angry at God.

Steltzer (2013) states that a good deal of anger is motivated by a desire not to experience guilt, and *beyond* this, the distressing emotions of hurt and fear. Supporting Stosny's (1995) argument that anger is almost never a primary emotion, he suggests that underlying the anger are - in the case in hand - core hurts of guilt and powerlessness of the father. Such feelings appeared to engender considerable emotional pain, mainly in relation to participants' anger toward others. On this level, anger is often directed "out there" as a self-protective action. Although malice may not have been the intention of these fathers, their actions were perceived as displacement of their grief and disappointment onto whoever did not live up to their expectation within the situation at that time (Steltzer, 2013). This may include the doctor delivering the diagnosis; people whom the father had expected support from; or complete strangers who simply reacted in a way the father found offensive at any given time, as illustrated by the following comments:

When the paediatrician told me that my daughter had Down syndrome my first instinct was to attack him...

I still feel resentment... of how my parents handled that time.

I also became furious at some reactions by other people...

Interestingly, only one participant explicitly renounced any feelings of anger, saying:

I was sad and worried...but never angry.

- **Physical subsystem**

Bracing for disability

A sense of anxiety and apprehension emanated from the language participants used to relate their fears during the diagnosis stage. This is in line with findings of Singer (2006) that the unexpectedness of the diagnosis threatens the perceived "security" of the family. Consistent with findings of Lang, Davis and Ohman (2000: 157), participants noted that their distress induced anxiety was triggered by something that was not yet specific. Thus, they were anticipating the unclear future with much apprehension.

I was scared...did not even know how to raise a normal baby and now I have a DS boy

I was overwhelmed by fear...

I was worried about the unknown future

I was scared...I envisioned a mentally retarded child who would walk in a daze behind her parents wherever they went...this was the only association I had at the time.

This was an absolute shock in terms of me not knowing what to do...I did not have a plan...

What was life going to be like? What other challenges did the doctors not tell us about?

- **Cognitive subsystem**

Ignorance about DS

Interestingly, none of the participants had been directly involved with anyone with DS prior to the diagnosis of their child. General unfamiliarity and ignorance about DS compounded fears and anxiety about how the syndrome would affect their own future and that of their child, and consistent with findings of Keller and Honig (2004), participants voiced their concern about the uncertain future as follows:

... I had no idea of what to expect of our lives going forward, and everything that indicated a possibility of a life worth living, I clutched at.

...we had no guidance about what DS actually was...Google is not the best tool in such time of crisis.

A lady came from DS Association and gave us the most hideous pamphlet which really depressed me. I wished I had a "manual" explaining DS...what we could expect from this child...how we could make her life better.

I had little knowledge on DS at the time...I was worried about the unknown future.

A state of fear, anxiety and uncertainty affects also the behavioural system of the father.

- **Behavioural subsystem**

Affecting the behavioural subsystem of fathers, the reality of the unexpected and unwelcome diagnosis necessitated a change in plans. This was acknowledged by fathers in different ways.

A change in plans

One participant's statement was especially indicative of intense negative emotions after the diagnosis disclosure. Clearly he had felt the unforeseen and the abrupt change in plans was beyond his control. From the way the father described his feelings at that time,

the researcher detected a sense of saudade in his reflection. This Portuguese term has no English equivalent but identifies the feeling of evocative longing for something past: a nostalgia that speaks of sadness; and in this case, may reveal the father's bittersweet yearning towards something over which he has no control; and a knowingness that that which he is remembering or pondering, may never come again (Collins English Dictionary 2014).

My son was in hospital for 10 days...I became very depressed...when I left the hospital I would become incredibly negative. I felt that DS had come and destroyed our family, who we were. Shortly before my son was born landscapers redid a part of our garden...I remember looking at his newly landscaped section and thinking "What a waste of money". In my head the pretty garden didn't fit with the sad, ugly picture of who we were now as a family...words like happy and beautiful didn't fit in with who we were now...more than anything I just wanted things to be how they were before he was born.

Immediate concerns

In response to the question "What were your immediate concerns?", a range of responses were elicited. Fathers acknowledged that a change in plans included concerns around the future of their child once they (the parents) pass away; the increased financial burden; logistic issues related to their child's condition; social acceptance of their child; and, the possible impact on the marriage and general family dynamics.

A majority of participants voiced deep concern around the burning question: what happens to their child if they are no longer here, which extends to the added financial constraint which comes with providing for the child for the unforeseeable future.

...who would look after him once we are not around anymore?

...who will guide and support him when we eventually pass away?

My biggest concern is if something must happen to me or my wife, what will happen to him...

Immediate concern...long term financial support and assistance...

Money is a problem...how will I be able to cope with all the challenges coming from DS...

Will we be able to afford special needs schooling?

Logistic concerns raised by participants related to future personal competence, capability and abilities of their child with DS and included aspects of education and independent living.

...will he develop well enough to live a life of supported independence as an adult?

Will she be able one day to take care of herself?

Will he be able to express himself?

This father is concerned about the child's delayed speech development. This child was still non-verbal at the age of six.

As mentioned in the literature review, fathers of children with DS share deep concern regarding the social acceptance of their child (Keller & Honig, 2004: 338). Commenting as follows, participants confirmed this association:

What will other people think?

Will he be accepted? Will he be bullied?

Some fathers were concerned about how this life event would impact their family and marriage.

How would we handle this as a couple?

Were we capable of dealing with the challenges to come? What was life going to be like? Was this the end of our marriage?

...I must ensure that my child won't rely on his siblings to have to support him later in life.

In response, Orphan (2004: 100) reminds us that it is healthy to feel afraid, as this often serves as springboard to problem solving. Anxiety (fear) and apprehension about the unexpected diagnosis provided some fathers with energy and strength to function and put plans into action. For example, two participants said:

Above all, my immediate concern was for him to get well and get home...I intended to read up about every kind of early intervention programme under the sun... we could all be together and get a routine going.

The morning after she was born I was over the initial shock and was ready to deal with whatever challenges would come my way.

- **Spiritual subsystem**

Turning to the spiritual subsystem, it is necessary to provide some concept clarification. According to Fisher (2011: 17), spirituality can be viewed in a variety of ways; from a traditional understanding of spirituality as a religious expression, through to a humanistic view of spirituality devoid of religion. The researcher believes that at their core, humans are spiritual beings, as it refers to the essential nature of human beings, their strength of purpose, perception, mental powers, and, frame of mind (McCarroll, O'Connor & Meakes, 2005: 43). According to literature, spirituality is posited at 'the heart of human experience' and it is experienced by everyone (McCarroll et al, 2005: 44). Evident from their narratives, many participants viewed spirituality as a fundamental, vital component of being human. Evidence from the participants' responses supported the notion that human spirituality, in a very real sense, unifies the whole person (Fisher, 2011: 18).

Acceptance

Related to this study, acceptance can be defined as the acknowledgement of the reality of the child's diagnosis (Orphan, 2004: 104). For some participants, acceptance was a cognitive decision:

Initially I was very apprehensive... accepted her condition... she is the love of my life now.

There is still some regret...but my emotional approach is improving...

For others, it was more of a feeling:

It is so important that he grows up knowing that we love him and accept him exactly as he is, DS and all.

Acceptance is the single most important factor to experience the gift of such a child.

Referring to the systemic model of individual functioning (See Figure 1.1), it was evident from their responses that the internal subsystems of the father are not only impacted by the diagnosis of his child, but also by his perception of the long-term effect thereof. Their concerns did not diminish once the mother and child were home and the wheels of family routine started turning. This was evident in the second sub-theme which developed from Theme One, which refers to the long term effect of the diagnosis on the father.

In order to establish whether there was a shift in perspective between the diagnosis disclosure and the actual fathering experience, participants were asked to describe how

the fathering experience of their child with DS affected them on emotional, physical, cognitive, behavioural and spiritual levels. Analysis of these responses follows in the section below.

Again, it is understood that the effect is not isolated to any one subsystem at any one time; rather, that the post-diagnosis experiences also affect different subsystems under different circumstances. As life span dynamics of intra-personal functioning refers to the post-diagnosis period, it refers to the reality of the permanency of the life event, and includes the most significant perspectives fathers recounted from this time. Although there is an overlap in the subsystems, the perspectives of fathers are once more related to the subsystem which is primarily affected according to their responses.

5.2.1.2 Life span dynamics of intra-personal functioning

In Chapter Two, Freud's theory describes how the unconscious contains the memories, emotions and instincts that are threatening to the conscious mind. Evident from the previous section, most fathers perceived the unexpected diagnosis of their child as such, and employed coping strategies (consciously or unconsciously – such as for example denial) to deal with this news.

Existing research recognises five themes that dominate contemporary research on disability/fatherhood studies (See Chapter Three). Two of these themes focus on the psychological well-being of the father, mostly in comparison to fathers of typically developing children. Narratives of participants were consistent with findings with regard to factors which attribute to elevated levels of parenting stress; as well as adjustment and acceptance factors related to an unexpected diagnosis and its accompanying challenges (Oelofsen & Richardson, 2006: 9).

This section looks at fathers' adaptation to the diagnosis as well as to their child. The literature emphasizes the importance of successful adaptation, which occurs when balance is achieved between the needs of the child with DS, those of the other family members, as well as the family as a unit (Mandleco et al, 2003: 367). Participants describe this long-term commitment as follows:

Having a child with DS is physically and mentally a big challenge. You have a child much longer in your arms and for life in your home.

...it becomes part of you and you build your life around it.

The manner in which this life event affects the subsystems of the father can be likened to an electric thunderstorm. The source of the storm is static, in one place – this refers to the diagnosis and the permanency of this life event. But the bright sharp strobes bolt into every subsystem of the father. These light tentacles not only illuminate the starkness of the current space, but also animates flashes of the future. Although these flashes may, at the time of diagnosis, only be flashes of a *perceived* future, most fathers acknowledge these flashes with anticipated feelings of fear that affects the emotional subsystem of the father.

- **Emotional subsystem**

Fear related to the future of the child

Without fail, every father made reference to their fears around the ability to protect and provide for his child with DS throughout his own lifetime and beyond. This finding, which implicates the conventional roles which the father has cast (predominantly that of protector and provider), emphasizes the importance of fathers coming to terms with their child's diagnosis.

Fathers perceived that their child with DS will for the longest time be dependent upon their help, resulting in their role as protector extending to their child's future physical, social and emotional needs (Grant et al, 1998: 69). The selflessness (thus concern for the child rather than for self) of fathers to protect their child was clear in their expressions of fear related to the future of their child with DS.

Will my son develop well enough to live a life of supported independence as an adult? What will he do as an adult once he has finished his school years? When my wife and I become elderly and eventually pass away, who will guide & support him then?

Will she be safe and taken care of? Will she end up in an institution where she will be abused? Will she ever be able to take care of herself?

... biggest concern... what will happen to him as an adult. What will he do? Where will he live? Will he be able to support himself?

An external reality which impacts the emotional and physical subsystem is the financial implication of raising a child with DS (Pelchat et al, 1999: 394), as then pressure to indefinitely provide financially for the child may imply that the father needs to continue

working for much longer than intended. Many fathers stated deep concerns related to adequate short- and long-term financial provision for their child with DS as follows:

In terms of putting measures in place for later in life, I constantly worry about money – will we have enough for him to be looked after we are gone.

I am always concerned about having to leave enough money for her to be well cared for in a safe place where she can be safe and happy. I have also had to pay for extra treatments and for tutors.

My main immediate concern... to ensure that I leave enough money after my death for her to be well taken care of.

... as a father (aside from the day-to-day support), you need to have a plan for the future for the child. With the increased life expectancy of a child with DS, it is likely that they will outlive their parents. They need a safe place to stay and enough capital invested to support them (i.e. through a trust) for the rest of their lives.

Expressing feelings

According to Dosser, Balswick and Halverson (1986: 241), being emotionally inexpressive is perceived a vital part of the very nature of 'manliness', defining an inexpressive male as someone who does not verbally express his feelings; either because he has no feelings or because he has been socialized not to. Being able to express emotions depends on the individual's unique capacity, as indicated by some participants:

Vocalizing the challenges that came with having a child with special needs made me feel like I was criticizing my son and highlighting his shortcomings.

I am a private person who only shares things very selectively...

I just switched off...the biggest challenges are in my head...

Fischer (2000: 166) defines this phenomenon as 'restrictive emotionality' since men appear to have difficulty expressing feelings openly, giving up emotional control and being vulnerable to self, others, and new experiences. Because so many men are socialized to ignore their feelings, they may not recognise their internal stress, strain, and symptoms of other related illness. One father acknowledged this as follows: *I internalized the emotional side... I don't think this was healthy.*

Realization of difference

One participant, as a teacher of typically developing children, reflected on the ongoing emotional conflict he experienced working with his students all day and then going home to his own child who was battling to meet his own developmental milestones.

...it was tuff... working with normal children every day and going home to your own Down syndrome boy was tuff.

Corresponding to findings of Cuskelly et al (2008) and later Takataya et al (2016), participants' realization of difference extends further than a simple comparison between the abilities of children. Some participants experienced realization on several deeper levels, especially regarding their perception of disability, and specifically in terms of labelling. Realization of difference thus implies acknowledgement of the long-term implication of the syndrome; acceptance of their child; and, the reality of the difference between who they perceived their family to be before the diagnosis, and how they perceive their family to be going forward. One father commented:

Previously, if I saw a person with disability I would try and be polite and not stare, which suited me, because thinking about disability made me uncomfortable. These days, when I see people with disabilities in public I wonder about them a lot, not so much their disability but who they are as people and how they've adapted their lives to accommodate their disability. It has made me aware of the danger of labels, whether those have to do with race, sex, disability, religion, sexual orientation, etc. The label hides the person and you miss so much if you can't see past that.

Another father noted that denial of the difference was neither helpful nor healthy. It appeared that this father acknowledged that the diagnosis impacted the entire family as a system; yet that accepting that their family was now different may bring a measure of equilibrium to the emotional subsystem of each individual member of the family as well as the emotional component of the family as a system.

The largest challenge is to some days stop and realise the impact of DS on our family...it is not helpful if you don't stop and realise life is different to other families.

Comparable to recurring episodic grief (See section 3.3.7), recurrent sadness of fathers was not uncommon. Friehe et al (2003: 214) noted that this sadness manifests as a continued process with no complete resolution and no predictable end, and tends to be revisited at critical life junctures (such as school plays, graduations, weddings, and so forth). One father noted:

There is a degree of sadness that is constantly with me, not always in the foreground, but always present to some degree.

Love, pride and inspiration

Consistent with similar research (Takataya et al, 2016; Blacher & Baker, 2007: 345), participants of this study shared touching testimonies of love and pride, indicating positive perceptions associated with being the father of a child with DS. Not only did this indicate acceptance of both the diagnosis and the child, but it extended further to fathers

acknowledging how they had been inspired by their child. Participant responses supported Jacques' (2003: 4-5) view of a relationship between positive perceptions of fathers and experiencing their child with DS as a source of joy and happiness. Comments below illustrate participants' increased sense of purpose and priorities; increased tolerance and understanding; personal growth and strength; and, increased spirituality.

I love her with all my heart... irrevocably proud of all of her achievements thus far.

I'm actually the lucky one to experience the impartiality love that only a child with DS can offer!

I have learnt to love differently...learning from my son how he loves and forgives easily, it has challenged me to be more loving in life to others. His ability to forgive and move on has challenged my concept of loving.

My son has brought a lot of love into my life as he just loves unconditionally. When I get home from work every day he runs to me and gives me a big hug...the highlight of my day.

... he is an inspiration because he never gives up... he keeps on trying until he can do what he wants.

The rare victories lead to extreme happiness and pride.

... my precious little boy... I love him with all my heart – no matter what – as simple as that. ... exceeding every expectation in every area, in every possible way. Had I known from the very beginning what would unfold so miraculously and fascinating before my eyes when first I heard about my son's condition I would most certainly have popped an expensive bottle of champagne at that moment, and toasted the utter privilege of a parent given such a gift.

- **Physical subsystem**

Physical demands

Meeting the financial implications was a concern that extended to emotional, cognitive, physical and behavioural subsystems in terms of planning, execution and logistic demands on the father. One participant stated that he needed to increase his work-load in order to accommodate the demands to provide financial stability for his family.

It is not easy to provide for a Down syndrome child because of all the therapies. I need to work extra, do extra coaching to earn higher income.

Research indicates that fathers view their most important contribution to their children's well-being as supporting them financially (Walker & McGraw, 2002: 565). Believing that his role as provider is in any way insufficient (thus compromising his family), may lead to

emotional and health-related issues (Jain et al, 1996: 431). One participant expressed feelings of guilt in this regard: *I feel guilty that I cannot provide well enough for my family that my wife can stop working and spend more time with our children. I regret my career choice and I wish I had gone for something more lucrative for us to be able to do this.*

In terms of the demand and frustration of increased physical demands, participants commented on increased physical exhaustion and feelings of being overwhelmed as follows:

Draining... at times he slept badly which affected our sleep...

My son couldn't tell us if he was cold, hungry or if he had a sore tummy... had to guess and predict everything for him... Sometimes he would cry and we did not know why... this was frustrating and traumatic. Having a child who is non-verbal adds frustration to the prevailing feeling of being overwhelmed by the child's physical demands.

I am constantly tired and I don't see this ending any time soon, which makes me want to weep.

Felt constantly guilty that I wasn't a good enough dad and did not spend more time with him...

One participant who battled to come to terms with the diagnosis for a variety of reasons admitted to increased alcohol consumption. As the father responded in his second language, it is inferred that he referred to alcohol consumption. He commented: *I do drink more than I used to...*

Seen against the background of his whole experience starting with the diagnosis, a possible explanation for increased alcohol consumption may indicate a form of escapism (as coping mechanism and distraction) and stress release for a father who felt overwhelmed by the enormity of such a life event (APA PsycNet, 2011). Although this study is unable to demonstrate conclusive applicability, the aforementioned assumption is reinforced by the further comment that he also now focussed more on exercising. Whilst this can be justified as a precautionary health measure, an intensified exercise regime may also be indicative of a means of escapism (APA PsycNet, 2011). The participant noted: *I focus a lot more on my exercise... (to stay healthy as a provider).*

To recap his experience: the unexpected diagnosis left him in an state of shock:...*shock, surprise, disbelief...*; his extremely negative experience with the paediatrician:...*I hate the doctor and the way she approached the situation...*; profound feelings of despondency:...*felt despondent...*; uncertainty about his other children's reaction to the diagnosis:...*how and*

what do I tell the older boys...?; having only his shocked wife for support:...my wife was my only support....

Post-traumatic stress

Carpenter and Carpenter (1997: 12) stated that chronic vulnerability is a constant state, a part of being the parent of a child with special needs. Generally speaking, fathers are often not aware of their own heightened stress levels and simply take it for granted as a part of everyday stress at any given time. Comparing the effects of post-traumatic stress (PTS) with participant narratives, especially the diagnosis distress and factors related to the future of their family and their child, there appeared to be a strong likelihood that some fathers experienced PTS. Garland (Orphan, 2004: 91), defined PTS as the experience of an event *outside* the range of usual human experience which is very distressing.

Unique (and particularly challenging) to the event of having a child with DS, the traumatic stress did not just happen in the *past*; it was simply now added to their ordinary stress in the *present* which was most likely to continue into the *future*. PTS can result from the implication of the diagnosis that the child is less than (the expected) perfect and will bear this label throughout his life.

According to Swartz et al (2011: 378), PTS manifest in three main areas namely feelings, actions and physical behaviour. Feelings influence the emotional and physical subsystem. These feelings, actions and physical behaviours may cause an emotional upset which can last for a short period (four to six weeks), after which the symptoms may diminish somewhat (as noted by participants). However, the ongoing traumatic stress of fathers does not rule out the actual possibility of lasting problems, or ongoing psychological problems (Swartz et al, 2011: 379). Although symptoms related to PTS may be intertwined and overlap with other subsystems, the following subsystems of the father were typically affected. **Feelings** impact the emotional, cognitive and physical subsystem; **physical behaviours** impact the physical domain; and, **actions** impact the behavioural domain (Stokton, 2014). To minimize duplication only a few applicable responses refer. However, indicators of PTS symptoms were correlated throughout Themes One, Two and Three.

Feelings related to PTS

Section 5.2.1 included experiences of fathers which were consistent with typical symptoms of PTS related to feelings, namely: mood swings, anger, suspicion, fear and irritability; overly emotional reactions; feelings of not being able to cope with everyday

situations that were usually manageable; emotional numbness or blankness; functioning but not feeling (Swartz et al, 2011: 379). Emotional numbness was evident in the comment of one father who preferred to not show his true feelings about this life event. To avoid negative reactions of others he chose to wear the mask of appearances. He said:

For me the hardest thing was dealing with people's reactions... to let them know how "fine" I was, when I actually wasn't...but more than anything I didn't want pity...

Another participant explained how he overreacted to seeing a family with a toddler with DS in a food store. It can be inferred that his reaction was driven by a need to connect to 'normalcy' of having a child with DS:

I saw a mother with two daughters, one with DS. I literally stalked them through that store!...they seemed happy and were doing normal stuff like shopping for food! It seems absurd now, but at that time I clutched at everything that indicated a possibility of a life worth living...

Physical manifestation of PTS

Physical reactions of the father included problems with sleeping and anxiousness. Previous sections referred to such manifestation of PTS. Feeling constantly exhausted may hamper clarity and decision-making about the situation and the future which compounds feelings of anxiousness. Participants commented:

... I am constantly tired...

*... trying to put measures in place for later in life... **never 100% sure** if it will be enough.*

Actions associated with PTS

Previous responses from participants indicated actions associated with PTS. These include social isolation or self-deception regarding the diagnosis, as well as reliance on alternative methods of stress release such as increased alcohol consumption or increased physical exercise regimes.

- **Cognitive subsystem**

In line with previous studies (Takataya et al, 2016; Muggli, Collins & Marraffa, 2009), the current study showed that once participants expanded their knowledge and insight of DS, their confidence increased and they felt more competent about their parenting task. Participants reported that significant shifts in perception resulted from their concerted efforts to become more knowledgeable about DS which included revision of their previous conceptions of the syndrome.

On a cognitive level I have gained a lot of knowledge on DS and it has made me come to love people with disabilities and to be much more compassionate to their needs.

I definitely know a lot more about DS than I did before...it's not like you have a choice! But it has definitely changed how I see people with disabilities in general.

From not knowing anything about disability and the effects of it in your life to living it has completely changed my way of thinking and experiencing life.

Self-criticism

Self-criticism in its most basic form refers to unfavourable or severe judgement of oneself, one's abilities, and one's actions (Collins English Dictionary, 2014). Fathers appeared to be harsh self-critics. One participant noted: *...these are the voices that keep me up at night...* referring to the 'voices' (his inner torment) that taunt him about his inability to 'fix' this situation.

Impacting the emotional subsystem, self-criticism is a significant force behind the manifestation of anger, guilt and other emotions of fathers in this situation (Murray et al, 1991). Berating the self for not being able to predict, control or 'fix' this situation ties into Parsons' theory of the perceived role of the father. Evident from the narratives of fathers, self-criticism related to the following issues:

Self-criticism for not meeting the needs of his wife: *...so caught up in my own misery that I completely missed my wife's concerns and worries at this time... I wasn't there for her emotionally...*

Self-criticism for lack of patience: *...some people are good with kids with special needs – they have the patience and compassion to persevere through the challenges to help the child develop. ... I am not that type of person... I really battled with this and did not have the patience to keep trying to do something with him... ended up doing less and less with him... major regret.* This father shared his regret retrospectively, as his child passed away.

Self-criticism for not being able to spend enough time: *I want to be there for him all the time... biggest worry is whether I will be able to do that.*

Self-criticism raised self-efficacy doubts to effectively parent their child with DS.

How am I going to bring up the child the correct way in this harsh world?

I felt very lost during the first few days following her birth because I did not have a clue what to expect and because there was no information which I could readily obtain to better understand what I was in for.

Were we capable in dealing with the challenges to come?

Some fathers came to the realization that a redefinition of their role as protector was required to support their child toward achieving a measure of independence and, eventually, autonomy as an adult. Participants realized that this fathering role calls for increased encouragement of their child towards self-competence, self-worth and self-actualization.

All I can do is make sure he grows up secure in being loved.

In one of the Proverbs the metaphor used is of a father who 'delights' in his son. He must know that I delight in him, that in my eyes he is everything I could wish for in a son, and that I have confidence in who he is and his abilities. I want him to know as he grows up that he is a young man with a purpose and that he has what it takes to make a success of his life.

Recognition of positive influence

Comparable to prior studies in the field, participants recognised the positive influence of being the father of a child with DS. Significantly, the overall tenor of participants' comments suggested a positive rather than negative perspective in terms of perceived life lessons (Skotko et al, 2011: 2339; Cuskelly, 2008; Hodapp, 2007: 280). These perceived life lessons will be expanded in section 5.2.4.1 in the section dealing with the parenting experiences. Although this manifests primarily in the cognitive subsystem, positive reactions and experiences also affect the behavioural and emotional subsystems of fathers. In this regard, participants referred to their own increased levels of tolerance, understanding, patience, awareness, and responsibility after becoming the father of a child with DS.

I try to be more tolerant and understanding.

...much more patient with him because of his slower processing of instructions/tasks given to him...

I have become more aware of the vulnerability of children with disabilities.

I truly believe that having a child with DS has made me a better person.

...learnt a lot about children with special needs... made us better parents for the other two children.

I take more responsibility and avoid silly things that may keep me away from being there for my son.

Addressing existential issues, one father provided a unique retrospective reflection after the passing of his child.

Having a special needs child definitely changes your perspective on life. You see things very differently. Before [my son] was born I associated with people that would help my career or had common aspirations to me. After he was born I associated with people that had similar challenges or people that could relate to the challenges. When he got cancer and then died, I saw life even more differently. I think a lot about wasted time. I think a lot about how I used to choose “catching up my email” instead of just sitting with him and being with him (before he was sick). I think a lot about how limited our time is and the decisions we make with our time. So often we choose to do things that bring no value to ourselves or others. Before he died, I thought that I would bring importance to my life (and family) by being successful and building a legacy. Now I realize that true value comes from having a positive impact on yourself and those around you. It is terrible that it took his death to bring me to this reality.

- **Behavioural subsystem**

The behavioural subsystem refers to the will and choices of the father, which leads to his behaviour in a given situation. The behavioural system is influenced by the emotional and cognitive subsystems as well as the physical demands and external influences of supra systems (Johnson, 2011).

Paradigm shift

A number of similarities were noted between research findings (Takataya et al, 2016: 7; Skotko et al, 2011; Van Riper, 2007) and responses of participants regarding increased positive behaviour resulting from their own paradigm shift toward disability and their child. Correspondence in increased maturity and increased awareness about disability in general was described by participants:

Before my son was born, my behaviour was selfish. I did pretty much everything for me. The responsibility that came with his challenges made me mature very quickly. My decisions were more centred on him and on his wellbeing and future.

Our lives become more structured because that structure brought him comfort...This routine not only helped him but also us in managing the challenges.

It has made me be a more careful in how I speak about disability, the terms and tone that I use... before I used to be more flippant. I am also very aware of how people speak about my son.

I can now easily accept differently abled people. Before having a child with DS my reaction toward disabled people was completely different. I was not able to be in the proximity of, or even hear about people with severe mental and physical disability without feeling queasy or losing my appetite.

Related to a positive paradigm shift, an interesting finding refers to the marked 'connectedness' between families with a differently abled child. It is not uncommon for parents to easily approach another family with a child with DS and effortlessly strike up a conversation. Even if the commonality is often only the diagnosis of their children, most parents of a child with DS will relate to this nebulous bond. One participant described:

Whenever I see other parents in the shops with a child with DS I have this urge to go and greet them, it's as if we belong to the same club.

Improved emotional state

Findings of this study corroborated the statement that, after an initial period of adjustment, fathers experienced improved psychological well-being, personal growth, changes in philosophical or spiritual values, and improved relations with others (Van Riper, 2007: 118). Furthermore, the philosophical perspective of most participants clearly indicated that fathers truly *strived* toward a state of acceptance. Inferred from the fathers' own words 'try' and 'day by day', their language indicated the involvement of both time and effort. According to Kramer (2008: 56), as repeated action, this also indicated a learned response which, over time, becomes habit. Combined with a positive attitude, these concepts steered fathers toward a change in perception. Evident from participant responses below, fathers tried day by day to find meaning and to change the meaning that they ascribed to this life event:

I try to be more tolerant and understanding. I have become more philosophical...less quick to judge... try not to rage or become angry quickly.

I take things day by day.

A challenge is to just see him for what he is... I'm getting better at seeing that, but some days are tough.

My emotional approach is improving...

Embracing the difference

Austrian neurologist, psychiatrist and Holocaust survivor, Viktor Frankl, is most famous for chronicling his experiences in a concentration camp which led him to determine the importance to find meaning in all forms of existence. Frankl believed that, no matter how brutal life treats you, there is always a reason to continue living (Redsand, 2006: 94). Related to this study, it appeared that reason to be positive transcended circumstance and diagnosis. Such a humanistic existential approach - that thought is where the power lies - has supported and been used by many philosophers to underpin the concept that the space between the *reaction* and the *pause* is where the real power lies. Relevant to the issue under study, it appeared that precisely between the reaction and pause lays acceptance of the child and his diagnosis. However, this appears to be possible only if the father is able to see his child *first*, and the DS diagnosis as secondary (Adler & Proctor, 2014: 187). Embracing the child with his/her diagnosis appeared to be a powerful catalyst toward acceptance.

...I completely accept him...I regard my son as a child/person first, and special needs later.

There is no greater feeling than having her in my life... she is flesh of my flesh and blood of my blood. She is part of me, as I am part of her... that bond will never change.

I just see him for who he is ...so much more than just this enormous DS label.

Some participants embraced the difference in a very practical way, thus empowering not only themselves but also their children with DS. While one father learned sign language in order to help his child to communicate (and vice versa), the other father's physical contribution toward the development of his own child (as well as for other children with DS) involved the establishment of an early intervention group.

When my son was born, my wife and I went on a signing course. (Communication with children with DS who are non-verbal is enhanced through simple signing. Makaton is a language programme using signs and symbols to help people to communicate [Makaton Charity, 2016]. It is designed to support spoken language and the signs and symbols are used with speech, in spoken word order. In this way parents and children can communicate straight away using signs and symbols).

The other parent explained:

...for our son's development to be optimized... we started a non-profit organization that provides individualized developmental tuition to children with mental impairment... Thoughts and discussions are now about how to provide/create meaningful employment for him once he has completed school.

- **Spiritual subsystem**

Many participants found solace in their faith and indicated that their faith brought them to a place of acceptance. Participants who experienced their journey on a spiritual level pronounced gratitude for their child as God's grace on this journey.

My life with Jesus Christ has never been the same. I have learnt to trust in Him on another level and am forever grateful for the route He allowed our life to follow.

God gave us a child with DS knowing that we are the right parents to raise such as child.

I am grateful for this special gift from God.

Some participants commented on their renewed spiritual reconnection with God as a direct result of having a child with DS. They said:

I trust in the Lord that He will enable us to do the best for our son...

I have become more spiritual... attend church.

My daughter's diagnosis with DS has strengthened my relationship with the Lord.

One father's experience included a premonition of 'being prepared' for his differently abled child. This influenced a significant shift in his faith.

This might sound weird, but I think that God has prepared me for many years for this, without me realizing it... as a teenager reading a book about a disabled child and being very moved and praying to God and saying that if he wanted to give me a disabled child that I would care for it... I spent time in London working as a caregiver, looking after the elderly and people with multiple sclerosis...remember reading a book about how caring for a disabled young made him realize that God values lives differently to people, he values us because we are His, not because of any achievement. My faith has deepened in the past 2 years since the birth of my son and my focus has shifted from striving to impress God to resting in my relationship with Him and to let Him love me.

Another father shared his perspective of how being the father of a child with DS affected him on a spiritual level, both at the birth and at the passing of his child.

My son's birth made me question God why this had happened. His life did not change my spiritual view. His death has made me confront mortality head on. At time of writing, I don't know if there is a God. But I am looking for answers. The thought that my son is just dead (with no heaven or any other after life) is too painful for words. But I don't want that fear to influence my perception whether God exists or not. I tend to believe that there is a higher power that is linked to our consciousness – but will probably always question the detail. Our limitations prevent us from fully

understanding everything and we don't know enough to have clear answers. I used to fear death terribly (especially as a child). But now the prospect of possibly seeing my son again one day has removed that fear. My son's life was a journey. His end has set me on another journey...

5.2.2. THEME TWO: INTER-PERSONAL EXPERIENCES OF THE FATHER

In response to the research question, it was relevant to determine how the inter-personal experiences of the father impacted his perspective of being the father of a child with DS. Inter-personal relationships are social connections with others that change continuously during their existence. Such relationships tend to grow and improve gradually as people get to know each other and become closer emotionally; or they gradually deteriorate as people drift apart, move on with their lives, and form new relationships with others (Levinger, 1983: 315). Human beings are innately social and are shaped by their experiences with others (Berscheid, 1999: 265). Feedback from the narratives of fathers indicated that support played a vital part in their perspective of this new fathering role and participants acknowledged the following relevant relationships: spousal relationship; the father's relationship to siblings of the child with DS; and relationship to friends and family.

Having a relationship with self is said to be the most meaningful relationship that one will ever have, and relationships with others helps to develop one's sense of self (Andersen & Chen, 2002: 619). Thus, maintaining a healthy relationship with self, ensures that one will also have the means to build and maintain healthy relationships with others, within different circumstances (Andersen & Chen, 2002: 620).

5.2.2.1 Relationship to self

Relationship to self refers to the part of an individual's self-concept that consists of the beliefs and feelings that one has regarding oneself. In this regard Gottberg (2013) refers to Chopra's clarification of the difference between self-image and self-esteem: self (image) is what other people think of you, and self (esteem) is what you think of yourself. Feedback from others cause self-esteem (who we think we are) to differ from the real self (who we truly are). Rogers (Swartz et al, 2011: 489) argues that everyone strives to reach an ideal self (who we would like to be). Incongruence between these aspects of self causes us to experience anxiety and tension. These feelings and beliefs develop based on interactions with others, and behaviours and emotions are shaped by prior relationships (Andersen & Chen, 2002: 619).

Ruptured sense of self

Feedback from the narratives suggests that some participants may have experienced a measure of ruptured sense of self. In other words, after the diagnosis of their child, there was incongruence between the self-image, self-esteem and real self. What had been perceived as the perfect family unit and the perfect picture was suddenly disordered by disability. Not only did some fathers feel ruptured (*disrupted*), but they perceived disorder of the family unit (disrupted and ruptured by this disruptive news). Some fathers found that the question to self: "What do I do now?" had no answer...

Two fathers sensed a perceived loss of control of what they thought were their perfectly constructed worlds. Their reality was much different. One father commented on his perception of disruption about everything he thought about his family:

I felt that Down Syndrome had come and destroyed our family, who we were... sad, ugly picture of who we were now as a family... words like happy and beautiful didn't fit with who we were now.

Another father felt vulnerable about his fathering ability:

You need to be a "super" parent to deal with all the varied issues...some people are just good with kids with special needs...I am not that type of person...

Feedback from others may influence the self-image and self-esteem. One father reflected on the effect of negative reactions of others, referring to anyone who mentioned anything negative regarding his son's diagnosis. His vehement reaction is consistent also of denial, insofar his claim to the 'tragedy rights' about this event. He said:

I got furious at some reactions by other people... I felt that we were the only ones who could say and feel this is a tragedy, but no one else has that right!

Within this relationship to self, fathers reported on noteworthy shifts in their expectations.

Shift in expectation

Related to the diagnosis of their child, some participants noted a personal shift in their expectation of love from unconditional love to loving (purely) without any expectation. One father stated: *...with the birth of my typically developing daughter I understood unconditional love for the first time. But with my son with DS I'm starting to understand how to love without any expectations.*

Another father noted that the unreserved way in which his son with DS loved, also challenged his own perception of love.

I have learnt to love differently... by learning to from my son how he loves and forgives easily. It has challenged me to be more loving to others. His ability to forgive and move on has challenged my concept of loving.

A shift in expectation of the abilities of his child with DS was noted by a participant as follows: *I have learned not to take small mile stones or the little things in life for granted.*

A message to friends indicated how he wanted to separate himself and his family from the expectations of others, by clearly stating their stance on the diagnosis and the way forward. Such an affirmative message sent a clear message of the father's attitude to the diagnosis and hence also guided the future behaviour of friends and family towards his child. The message that the father texted to friends and family to announce the birth of their child (and subsequent diagnosis) concluded as follows:

...While we are having to adjust to this news, it is not bad news for us. We believe that special children choose special families and we are honoured that God has entrusted us with the responsibility of caring for this boy. We know that great things lie ahead and look forward to caring for our son who is slightly different to his siblings. He will add depth to our family and we look forward to the journey.

5.2.2.2 Spousal relationship

The central relationship within families is the spousal relationship (Cuskelly et al, 2008: 105). Very little was found in the literature regarding the spousal relationship of families with a child with DS other than related to psychological reactions of parents and/or parental mental health and psychological functioning (Van Riper, 2007: 118). A meta-analysis conducted by Risdal and Singer found that the published data on marital functioning in families with a differently abled child is somewhat skewed by the negatively biased assumptions of researchers, and that when these biases were addressed, the negative consequences for this relationship were substantially less than thought (Risdal & Singer, 2004: 96). Consistent with studies by Van Riper et al (2007) and Kersh et al (2006: 884), participants of this study reported that the birth of their child with DS posed no threat to the spousal relationship other than related to personal stress issues. The following aspects were noted by fathers in relation to the spousal relationship: emotional understanding, limited time, and enhanced relationships.

Emotional understanding

Sustaining feelings of love in an interpersonal relationship requires effective communication, emotional understanding and healthy conflict resolution skills (Eisenberg, 2007: 72). Some participants recognised that by being mindful of their wife's emotional distress, they were able to support their wife during the diagnosis stage and thereafter. Acknowledging that emotional understanding also meant accepting and respecting the individuality of the other person's process (Snyder & Lopez, 2007: 299), one father commented:

My wife did not really want to talk to anyone... needed time to come to terms with it. I wanted to understand the practical challenges. I never felt that I needed to talk to someone... I internalized the emotional side and I think this was unhealthy. You have to be supportive... You need to know your spouse really well. If you sense they are battling then you need to let them talk and vent. If we were battling then we would share this and try and come up with a way to make things a bit better. Sometimes [my wife] did not want an answer – she just wanted to talk. I needed to understand that.

Due to the unmet emotional needs of a father, his sense of apprehension about this event may have been compounded by the fact that his wife was the person who disclosed the diagnosis to him. Thus, his emotional unavailability to support his wife at this point may have been the result of negative transference of the connotation of the diagnosis. It appears that his emotional withdrawal from the mother - the only other person truly in the position to understand the enormity of this life event for their family - may have been a form of denial that this was happening to them.

I was so caught up in my own misery that I completely missed her concerns and worries at this time. Looking back I think I wasn't there for her emotionally whenever she voiced her worries and concerns over how this would affect us or his future. I switched off emotionally as I just felt that I could not deal with her concerns and worries on top of my own.

Limited time

Fathers reported that the exasperation of having to cope with a new baby was exacerbated by the added distress caused by the diagnosis. As noted in the response of one father, uncertainty about how to raise a baby with special needs caused over-compensation in intensified therapies for the child, which leads to emotional and physical distance between spouses and is likely to influence the emotional, cognitive, physical and behavioural subsystems of the individual. Participants articulated these issues as follows:

...initially created a distance between my wife and I... both had this heartache we needed to deal with. Then it brought it closer. Now it just makes us busy... fit in physiotherapy, occupational

therapy, speech therapy and Baby Gym into a week is insane... Which creates distance again...constantly tired... don't see this ending any time soon... makes me want to weep.

...the time that you spend with each other is limited because most of your time is spent on the children... it can be a challenge...

Although the detail was not entirely clear, the father who lost his son provided a unique perspective in terms of how such a tragedy affected the spousal relationship. Understandably the logistics of having other children besides the child critically ill in hospital for protracted periods caused an inordinate amount of stress for the parents. This perspective was significant in that it provided a glimpse of what the reality is like for countless fathers of children with multiple diagnoses, or who have multiple comorbid serious health issues aside from having DS. Evident from the reflection of this participant, the demands of such circumstances may spill over into every subsystem. The father reflected as follows:

I don't know what my marriage would have been like without my son. There is a part of me that thinks he galvanized our marriage but there is also a part of me that thinks his death may have fundamentally changed me and my wife in ways that could influence our future. The tough part was the cancer treatment. My son was in hospital (sometimes for weeks), my wife and I would alternate at hospital. She would be there during the day, I was there at night. It was exhausting spending a night in hospital and then having to go to work the next day. I generally would sleep in the same bed as him and he was sometimes awake at night. My wife and I hardly saw each other....

Enhanced relationship

Majority participants acknowledged improved spousal relationships, implying re-establishment of equilibrium in the physical, cognitive, emotional and behavioural subsystems. Fathers reflected on the positive repositioning of their spousal relationships as follows:

...brought us closer, sharing experience and facing it together has helped us.

...opened a new dimension in the relationship with my spouse... a trust relationship with one another.

...our patience with each other has been tested quite a bit.....but decided to stand together...

I believe it made my wife and me closer.

... our relationship greatly improved in this time. We drew nearer to one another...overall good for our relationship.

5.2.2.3 Father's relationship to siblings of the child with Down syndrome

Fathers acknowledged that sibling needs included support, inclusion and an understanding of their unique contribution to the family system (Clarke, 2009). The children (the child with DS and any siblings) represent the supra-system of the father, which invariably influences all the fathers' subsystems in different ways at any given time. No empirical evidence exists that having a child with DS in a family automatically produces ill effects (Gannon, 2008). Fathers agreed that they found that siblings had favourable self-concepts and strong relationships with their brother or sister with DS (Cuskelly et al, 2008; Skotko & Levine, 2006).

Empathy

Some participants expressed empathy with the siblings who have to grow up with a differently abled sibling.

Inevitably I compare what I felt like at a similar stage of growing up with other boys...there is some regret and recognition of it being different, but my emotional state about this is improving. The siblings are both boys in their middle childhood.

As a father it is also hard to observe the effect on our other son...some days he just wants a "normal brother". However, the blessings far outweigh the challenges and every milestone is a milestone for the whole family. The sibling is three years younger than the child with DS.

I felt like my daughter was robbed of a 'normal' relationship with a sibling. The sibling is two and a half years older than her brother with DS.

Equal attention

Participants referred to ways in which they try to accommodate the needs of all of their children. While considering the important role that the father plays as provider (which keeps him away from home and at work), it is essential to bear in mind that the siblings also needed quality alone time with him. In order to spend some quality time with the siblings, one father instituted a bath-time ritual with the siblings.

I always made sure I was home at bath time for their bath-time ritual.

Participants acknowledged equal attention to the siblings was often a challenging pursuit. Similarly, they mentioned that social outings were limited because of the child with DS, which led to frustration and irritation as stated below.

We battled to do things as a family at times. Our options were always a bit more limited...restricted....a frustration that would make me and my wife short tempered. We sometimes had to do things separately...I would stay home with my son and my wife would go out with the other two children.

We do not visit people or go places too much...my son is very busy at times so it can be a challenge.

Gratitude and balance

From a family systems perspective, the relational life of families provides the central ecological context in which children are nurtured (Minuchin, 1985: 289). The family system is influenced by the attributes each individual brings as well as the family members' perceptions of those attributes. The birth of a child with DS is likely to affect the family system in numerous ways; from the micro level of dyadic interaction to the macro level of the cultural views guiding the fathers' perception about his differently abled child (Glidden et al, 2006: 949). One participant acknowledged that they were not maintaining sufficient balance between their preoccupation with the needs of the child with DS (therapies) and the emotional needs of the sibling. Moved by the reaction of the young sibling, the father shared his perspective as follows:

We were always busy. It created a lot of anxiety for my daughter who was two and a half at the time as she could pick up something was wrong but she didn't know what.

Due to the needs of the child, generally child with DS receives more attention than the siblings, and all too often the family script is centred on the DS theme. Participants acknowledged that they needed to make a conscious effort to maintain balance between time spent with siblings and the child with DS. They commented:

...I am more conscious about spending time with her alone, because we spend so much time with her brother with DS in therapy.

I find I am spending too much time with my son with DS. This has generated guilt in terms of not seeing more of the other boys...

Although participants recognised that the child with DS has a special place in the family, they similarly acknowledged and appreciated the inimitable gift that is so easily taken for

granted: the miracle of a typically developing child. Noting the uniqueness and value of every family member, fathers reflected as follows:

It makes me thankful for every step of my other daughter's development...

We are a family of four individuals, not just one (with DS), and the needs of all four of us are valid. I must make sure that we have balance and that everything doesn't only revolve around him, because then we are raising a narcissist.

My son is such a natural part of our household.... loves me and the siblings more than you could ever imagine... "favourite" in the family circle. This child with DS was born to parents in a second marriage and has adult siblings.

... love that child (with DS) with all our hearts – just like we love our other child.

Observing positive relationship between siblings

In line with findings of Hannah and Midlarsky (2005: 88), participants of this study reported positive relationships between siblings and the child with DS. Participants affirmed their observation as follows:

His siblings are very protective over him. They adore him, play with him, wrestle with him, play with his balls and toys together, and greatest of all, they are not shy or embarrassed to "show off" their baby brother to all and sundry. The most common word or expression you will hear at home is, "ah man cute". This father is referring to the adult siblings from a previous marriage who unquestionably dote on their little brother with DS.

It has been very good to see how our daughter has taken some responsibility to help with the raising of her 'special' brother, standing up for him when necessary but especially playing a lot with him. She does not see him as a 'mentally retarded' brother to shy away from, but someone to have fun with.

My son with DS has a younger brother who helps him a lot...helping him cope with difficult stuff. They are very good friends and work well together.

5.2.2.4 Father's relationship to friends

Unmet expectations of friendship

Friendship is a relationship of mutual affection between people and refers to a strong interpersonal bond characterised by affection, sympathy, empathy, honesty, altruism, mutual understanding, compassion, enjoyment of each other's company, trust, and a

space where one has the ability to be oneself, express one's feelings, and make mistakes without fear of judgement from the friend (Bennett, 2013). Whilst people with close friendships are happier, the absence of friends can be emotionally damaging (Bennet, 2013).

Feedback from participants generally pointed to appreciation of supportive friendships during this difficult time. However, one participant voiced his discontent about close friendships that failed his expectations when he needed them most. Distinct feelings of bitterness and disappointment were evident in this participant's reaction. It was evident that he perceived these 'friendships' as dismissive and disregarding of his emotional distress at a time when he explicitly needed their support. It was evident that the participant felt emotionally vulnerable, confused and let down by friends he had obviously expected support from. However, he noted that actual support came from an unexpected direction. He said:

I still feel bitter about the lack of support that I received from almost all of my close male friends. Only two of them regularly sent me messages to ask how my son and I were doing, while the rest just dropped off the face of the earth. I felt incredibly alone at this time as I tried to be strong for my wife and daughter, but I had a great need for one of my friends to just take me out for a coffee so that I could talk about how I was feeling. I found it ironic that I had almost zero support from my Christian male friends, while the two supporting me were the most un-churched.

Some fathers found that their social circle shrunk somewhat after the birth of their child with DS. This result may be explained by the fact that fathers became more selective and critical of the people they let into their lives. As explained by Dowling et al (2004: 145), they may also have felt that time had become too precious to continue unproductive or non-supportive relationships. It was difficult to explain this result; however, it may have hinged on some friendships simply not being strong enough to sustain anything out of the ordinary, such as a diagnosis which they may not know how to react to or talk about. Discomfort and ignorance about disability may also have been the cause for disintegration of insubstantial friendships (Pelchat et al, 2003: 240). Participants expressed their feelings about support from friends as follows:

With friends there has been a sifting. The friends who just accept him for who he is and love him because he's our son have grown closer. The ones who see him as a tragedy that has befallen us have grown distant. I just have no desire to see them, as I don't want my son around people who see him as someone to be pitied.

*We never discuss our child's situation with our friends...our friends never ask about our son...
Friends tend to talk around the situation*

Appreciation of supportive friendships

While one participant was 'wounded' by the lack of male friends' support, others had a different experience. As majority participants expressed their appreciation in this regard, it was reasonable to conclude that the majority of fathers were adequately supported by their friends. Participants commented about this interesting and valuable finding as follows:

Their continued prayers and support helped us tremendously. Their unqualified love and acceptance of our 'special' son has just been fantastic.

Our female friends were great at supporting us through visits, calls, sms's and dropping off meals.

Family & friends were hugely supportive.

...support we received was amazing...family, friends, work colleagues...

Development of unexpected friendships

Estrangement from one group of friends is often compensated for by the development of new relationships with people more willing to see the world from the father's new perspective (Dowling et al, 2004: 145). Participants reported about a notable kinship with persons with whom they now shared similar interests, most frequently, other families of children with DS.

...we became close friends with other parents with children with DS

...the informal coffee chats with other parents are probably the most supportive and productive friendships.

Social disconnect

The present study was designed to determine the perspectives of fathers of a child with DS, which is invariably constructed also by his view of his position in the social system. The interpretive lens that gives meaning to his subjective experiences is narrower than required for this specific purpose, thus only a broad interpretation is offered at this time. It has been documented that fathers' acceptance of their child is based on the child's social acceptability, and thus any deviation may influence a negative definition of the situation for many fathers (Pelchat et al, 2003; Saloviita et al, 2003). An interesting and unusual reference was made to an idiomatic expression by one participant. He said: *To put it plainly, we can never be the Jones's – for the majority of people we will always be less than the perfect family because of my son, so why even try?*

According to Mason (2000: 124), *keeping up with the Joneses* is an idiom referring to the comparison to someone else (usually a neighbour) as a benchmark for social standing. To fail to 'keep up with the Joneses' is perceived as demonstrating socio-economic or cultural inferiority. Despite the father's seemingly insouciant reference to their 'diminished' social standing as a result of their child's diagnosis, this statement may infer a sense of wistfulness because 'belonging' to a certain 'social standing' is no longer within their 'social' reach – all because of their irrevocable reality which includes an additional chromosome.

The researcher viewed this father's statement through different lenses. At first glance it suggests an attitude of *comme ci comme ça* (here loosely translated to mean neither good, nor bad, so whatever), which is reinforced by a shrugging closing rhetorical question (so why even try?). Viewed at closer glance within context of this participant's earlier statements referring to feelings of bitterness over unmet expectations of certain friendships, an undertone of fracturedness, hurt and cynicism was palpable. This view implies that his family were part of the Joneses clan before the diagnosis of their son. However, the diagnosis had now cost them their 'membership', and no amount of effort to regain their status as Joneses would ever afford them their position again. The permanency of the diagnosis ensured the futility of such effort, *so why even try?*

At this juncture it is important to mention that this participant displayed uncommon candour (extremely rare in similar studies) in his responses. Considering his initial lack of knowledge about DS, it was also possible to merit his reference to "less than perfect", against the backdrop of literature which generally paints a bleak picture of DS (Cuskelly et al, 2008: 108; Saloviita et al, 2003: 309).

Turn the kaleidoscope one more time, and the view tells the story of a young man whose aspirations of fatherhood no longer fit those of other fathers of his former group. This view showed someone who came to realise that maybe being the Joneses meant fitting into an imposed mould. Hence, the realization that certain friendships were fickle, may have caused a shift for this father. Interestingly, his language did not say "We could never keep up with the Jones's" (as the saying goes); rather, it appeared that within their group, his family may have *been* the Joneses that others were aspiring to keep up to. Alternatively, it may also have meant that, because of his son's diagnosis, his family no longer qualified to meet the requirements of being the Joneses. Thus, had this been a previous aspiration for his family, their new status as 'less than perfect family' now revoked that opportunity. A final turn of the kaleidoscope showed a father who reached the conclusion that just

maybe being the Jones's was no longer his desire for his family after all. The realisation (or perception) that his family were no longer contenders in the 'Joneses race' may imply that his acceptance of his son's diagnosis (and thus also the 'imperfection' of his family), also allowed him to acknowledge and accept his own 'imperfection' and fallibility.

Hence this participant's statement also indicates a father's step forward toward a healthier relationship to self, which included taking ownership of his reality, seeing it for what it was (a diagnosis), and, that it was his choice to be part of 'the Joneses race' or not. The participant closed his statement by adding...*So we just do what works and sod the rest.* Judging from this participant's previous accounts, this shift significantly indicated restored congruence in his self-esteem and self-image. And full acceptance of his new situation. Beattie (1992: 107) articulated the significance of such profound insight as follows: "The measure of self-esteem is determined by self-knowledge, not the opinions of others; because, essentially, we only need *our* approval."

5.2.2.5 Father's relationship to family

A family generally consists of more than just a mother, father and children. It is common for grandparents, uncles and aunts, cousins, and parents-in-law to be part of the family picture to varying degrees. It stands to reason that these people have their own reactions and perceptions of disability, and their input often has significant impact on the father's perception of this life event. Participants acknowledged extended family members as a source of emotional, physical and moral support and encouragement.

I confided in my close family members and friends who were very supportive.

Friends and family were very supportive emotionally...I don't think there was much more support anyone could have provided.

My in-laws were visiting us at the time... were great at supporting us and looking after our daughter while we spent lots of time at hospital.

My mother, sister and sister-in-law visited often and gave enormous moral support and encouragement.

5.2.3. THEME THREE: COLLECTIVE EXPERIENCE OF DOWN SYNDROME

Participants of this study confirmed that gaining information about DS was important to them at the time of diagnosis and thereafter in order to make sense of the syndrome and

to prepare them for what lay ahead. Corresponding findings documented that gaining knowledge on the developmental progress of their child replaced the initial negative image of DS for fathers (Takataya et al, 2016: 6). In this section we look at the participants' experiences of support from other families of children with DS, support from the medical fraternity and educational institutions, and their perception of support groups.

Most fathers appeared to identify with the accurate illustration provided by a father with a child diagnosed on the autistic spectrum when he said: *"I am just as I was before I had this child with autism, I am not particularly wonderful, or brave, or patient and I am not an expert. There was no training for this 'job' and I did not choose it; nor can I walk away from it when I feel I can no longer cope because there is no one else, and I love him, but it does me no good to be called a hero; it just allows others 'off the hook', because they can pretend I am coping and leave me to it"* (Jordan, 2001: 191).

5.2.3.1 Experiences of support

Support from parents of children with DS

Findings of this study were consistent with findings of Takataya et al (2016: 6) that a father who is not supported during and after the diagnosis process can feel fundamentally alone. Across numerous other studies (Skotko et al, 2011; Cuskelly et al, 2008), this study also found that fathers yearned for support from someone who truly understands; someone who has walked this road before. Participants commented:

...it would have helped me enormously if there was another father of a child with Down Syndrome I could talk to...

I needed advice/guidance from people that had already had children with DS on what to expect raising a child with DS.

... you want someone who is walking this road as well...

I would have liked to speak to reasonable, empathetic people who had been through something similar... experienced individuals... a kind and caring contact to share their experiences.

A number of participants were fortunate enough to meet with very positive parents of children with DS. Participants described such encounters as pivotal to their shift in perception toward both the syndrome and the future outlook for their child. It was evident from the responses that speaking to other parents alleviated the element of anxiety and uncertainty.

One visit that made a huge difference to us was by an occupational therapist who has three sons of her own, one with Down Syndrome. She listened, asked questions about us, answered our questions to the best of her ability and shared some of their journey with us. She basically made us realize that there might be light at the end of this tunnel after all.

The largest, most helpful support was when a family with a beautiful Down syndrome daughter took time to visit us to introduce us to the joy of such a child. They had experience, gave moral support & offered a wealth of knowledge that impacted and changed our lives and our thoughts on people with DS.

One person did however gave myself and my wife very good support and good guidance. This mother of an adult daughter with DS actually gave us hope again and made us believe that there can be a wonderful future with our child if we are prepared to believe it and see the positive and not to continuously focusing on the negative.

Not all participants reported positive encounters with parents of a child with DS. One participant was visited by a representative from a support association who herself had had a very negative experience with her child with DS. He shared his unfortunate experience: *The only support that I had was my wife and a day or two later a lady from DS Association came to see us and gave us the most hideous pamphlet which really depressed me...*

Support from wife

Participants reported that their primary support was their wife, which was consistent with previous research findings (Takataya et al, 2016: 6).

My wife was far and away the most important support.

The only support I had was my wife...I could only confide in my wife.

I don't recall really confiding at a deeper level in anyone aside from my wife.

Some participants admitted justifying their own inability to deal with the situation by over-reliance on their wife, which is consistent with research by Brown et al (2010: 135) who add that such an assumption may add further emotional trauma for both parents, which, in turn, may lead to relationship problems such as withdrawal from each other and miscommunication moving forward.

I did not have any knowledge of DS... I did not know what to expect and how to treat the baby... I trusted that my wife could take care of a baby even in this situation. I was an absent father who worked in JHB and went home to the coast on weekends.

Medical fraternity

Participants indicated the enormous influence that health professionals had on their perception of their child's diagnosis and condition, which was in line with findings by Takataya et al (2016). For many, dealing with health professionals was a source of stress (Barlow, Powell & Gilchrist, 2006: 61) and thus mostly impacts the emotional subsystem. Participants reported both negative and positive experiences in dealing with the medical fraternity. These findings were noteworthy given that health care professionals are the first port of call for the parents, and the father needs solid and balanced information in order to make sense of the diagnosis, and also with a view to the future of his child's condition. Participants indicated that the diagnosis was not always provided from a balanced perspective, but rather leaned toward the negative, which has the ability to profoundly influence the perspective of the father regarding the diagnosis as well as his child.

Participants stated that information from medical professionals lacked substance and that the words used by paediatricians wanted for compassion. For example, one participant recalled how bewildered they were when they were given the diagnosis at twenty weeks of gestation by an uninformed doctor who then suggested an abortion:

Our initial experience with our doctor was not helpful... informed at ± 16 weeks into our pregnancy that there was a problem... referred for an amnio... at 20 weeks it was confirmed that our baby had down syndrome. Due to total ignorance on our side as well as having a doctor who himself was not well informed, we were overcome with total fear, uncertainty and bewilderment... If he was better informed we would have had a better start. It would have been much less traumatic not getting advice to terminate the pregnancy...our immediate concern was where do we find out helpful information.

Another participant commented about the tactlessness of their doctor who revealed the diagnosis of DS to the mother without his supportive presence. Insensitive to the impact of this traumatic news, the doctor did not even wait until the father arrived at visiting hours. Despite the doctor's justification that he wanted to give the parents time to enjoy the birth of their son, participants described the lack of integrity displayed by such behaviour. Not only did the mother have to deal with the diagnosis by herself, but she had to be appropriately composed to break this devastating news to the unsuspecting father the next day. The father recalled:

They hadn't wanted to tell us the previous day... they believed we needed a day to just enjoy the birth of our son, before making us aware of possible complications. All of this happened while I was at home with our daughter the Friday night. When I came to visit the Saturday morning, my wife said that there was something she needed to tell me – and she told me...my wife was crying and I was just numb... completely overwhelmed by the devastating news.

Although the detail was unclear, another participant described their paediatrician as a “sociopath” and used strong language to relate his experience. It was inferred that the manner in which the news was broken to them was offensive and insensitive (the participant declined to provide detail). It appeared that the paediatrician shared her suspicion with the parents immediately after the birth, and the participant’s shock was clearly compounded by the devastating manner in which the news was conveyed three days later. His disparagement was clear:

Having less of a sociopath as a paediatrician would have been helpful. I actively hate the doctor we had and the way she approached the situation and dealt with us.

Participants expected and required support from the medical fraternity which included knowledgeable information, sound advice, focused direction for the immediate and long-term future, and empathetic guidance. A positive relationship with health professionals is an important part of building a solid support team. A relationship of understanding and respect from both sides is vital for the emotional, cognitive and physical stability of the father. The following comments clearly showed that these expectations were not met:

*I was concerned...what other challenges were we going to face that the **doctors did not tell us about?***

*Gynaecologist could have provided us with the names and contact details of persons or support groups for people raising children with DS. Also details for early intervention activities to aid their optimal development... as well as institutions offering early intervention programmes. **This did not happen.***

*...I would really have liked a pamphlet or book... what to expect... wanted to know the short, medium and long term challenges of having a child with DS... Also a list of doctors and therapists with their areas of expertise & contact details. **Doctors were not forthcoming with info.***

Educational institutions

Article 24 of the United Nations Convention: Rights of Persons with Disabilities clearly states that individuals with disabilities are not to be excluded from the general education system but must have access to inclusive, quality education on an equal basis with others in the communities in which they live (United Nations Convention Document, 2007). This law is most frequently ignored and educational rights of children with DS are marginalized on a daily basis (Nolan, 2006: 30; Kliewer, 2001: 5). Almost every parent of a child with DS will tell a tale of repeated denial of access to schools on the most insubstantial

excuses, or of 'inclusion' where the child is merely accommodated and not taught. Parents not au fait with the rights of their children, have found the challenge to secure decent education for their children a most distressing concern.

Most participants voiced their concern regarding the educational concerns of their child with DS, referring specifically to finding appropriate schooling.

...we battled to find a school that would accept our son...

...major challenge is to get a suitable school for her where she can reach her maximum potential and still be happy...

...it is a big problem finding a school that will take him...

Support groups

Interestingly, none of the participants were members of either a structured or informal support group, despite their names appearing on the database of one such group. The open-ended question regarding what they perceived as the benefit of a support group and if they would join such a group, elicited a variety of responses. Only two out of the eleven participants indicated that they would not join a support group. One participant cited his personality type and cultural disposition as reason in his response. He explained as follows:

This may be a personality and a cultural thing...also linked to ones upbringing...a very private kind of person...not be easy for me to participate in a group...DS situation of my child...I deal with everyday...do not want to discuss this with a group of strangers...I am uncomfortable with the idea of listening to other dads talking about their private experiences...Maybe my view will change someday but for now this is how I feel...

The other participant's apprehension was related to the focus of such a group. He voiced his concern that the focus of such a gathering could become father-centred rather than child-centred. His opinion was:

...not know if I would join such a group... meeting people with Down syndrome children some of them make their situation about themselves and not about the child...

Participants who were ambivalent about their stance on support groups seemed to prefer a one-on-one arrangement. Considering the entire narrative of each of these participants, their apprehension could be associated with their reserved and private personality types as evident from their responses. Interestingly, two out of the three participants who were nebulous about joining a support group of any kind, were husbands to wives who had, in

the past, initiated formalized parent support groups for families of children with DS. Participants had very specific ideas about the type of support group they would join and made valuable contributions toward the ideal framework for any future endeavour in this regard. Participants commented on their preferences as follows:

...I don't see myself as someone who would reply on a group...better to get on with life than to be weighed down by the syndrome...I would be cautious about the environment where DS is focused on regularly...such a group...danger of it being or becoming an environment where people become focussed on 'victim' mentality. I do however not have a problem with being part of assisting or sharing, particularly with new parents.

...would not join a group at this stage...probably would have when my daughter was born just to get to understand the condition quicker and more practically...willing to meet with new dads on a one on one situation which better suits my personality...there should be a support group of families rather than just fathers so that a wider perspective can be gained within as short a period as possible.

If the group will have topics such as Rugby, Tennis, Golf etc. yes, then I may consider...sitting in a circle and everybody need to share their feelings then I don't think I will attend because we need to focus on the positive and feel normal about the situation...I found that men will open up with sensitive issues much easier in a friendly environment over a long period of time. The environment needs to feel normal..."Golf days" Rugby Game or Bushveld / Hunting Trip to set the scene and then afterwards open discussion on Down Syndrome...decide what the aim of having a group like this is... personal point of view would rather be to have a good trusted friend (Male), to whom you have the boldness to share your feelings with.

Participants who indicated keen interest in such an initiative offered sound advice and practical suggestions on what would make such a structured gathering meaningful for them. Participants suggested the following:

...would have to be like-minded fathers...I don't like bringing my private and personal feelings into the open...would need to feel like a safe place to share

...group would only be successful if it had a purpose beyond emotional support...group of men that got together to do something good for children / adults with special needs then I would be interested. The "supportive" element would happen as a result of the organizing and auctioning the activities – gives men an opportunity to get together and chat, but not in a focused and controlled way.

I would definitely join...place to talk with other dads would be cool...maybe also some space for the families to get together...the answer lies in community with other fathers of children with DS...a

place to talk, ask questions, brag about your child and sometimes cry a little bit... A place to get perspective...also helps to see children with DS that are older than your child, to see them laughing, playing and interacting with their families.

... it would be very helpful to receive guidance from fathers that have DS children that are older than mine... share from their experience on how they dealt with the various challenges of raising their children, from baby to toddler to youngster to teenager, as well as what is available for these kids to do work wise when they have finished their schooling... have they managed to achieve 'supported independence' for their children? Does it work or is the child still fully dependent on parents and/or siblings when reaching adulthood?

I would join such a group...It doesn't matter what it offers... It's just good food for your soul to collaborate with other fathers that shares in your interest and that have experienced the same battles in life.

5.2.3.2 Community reaction

Participants confirmed that they were apprehensive about social attitudes toward their child with DS.

Initially I was very apprehensive when anyone would look at her...

It is not uncommon for people to openly stare at their child with DS (Takataya et al, 2016: 6) and studies have shown that parents often have to contend with whispers of pity, revulsion or mockery. Unfortunately, this is often reinforced by the tragic imagery commonly used in the advertisements of charities as well as the emotive language used in the press, referring to the differently-abled as 'suffering' from disabilities or 'confined' to wheelchairs (Woolfson, 2004: 5), when, in effect, the only thing they 'suffer' from is the 'confinement' of empathy from society. Participants share their experiences of an unyielding society as follows:

I have been challenged to forgive people who don't know about Down syndrome and have made ill-informed comments about my child's condition.

...phrases like, "special children are born to special parents" and "God would not give you a challenge you could not carry"...heard this many times...carry no real value...clichés.

The outside world is so ill informed of DS and judgmental. How this ignorance will affect my son's changes of being the best that he can be in life concerns me a lot.

A study by Baker-Ericzen, Brookman-Frazee and Stahmer (2005: 198) found no relationship between stress and the level of social skills in children with ID. In contrast, findings from the current study confirmed that fathers stressed about the social skills development of their child with DS. In the spirit of a protector, fathers were hurt when comparisons are made between their child and society's conception of a typically developing child. Fathers shared their views in this regard as follows:

...important for society to know the truth...most people think that persons with DS will never be able to look after themselves...not entirely true.

...protecting him extends to educating his peers, their parents, his teachers and our friends to break down prejudice and misconceptions. I want him to know as he grows up that he is a young man with a purpose and that he has what it takes to make a success of his life – even though that success may not look like other people's idea of success.

5.2.4. THEME FOUR: MANAGING THE LIFE EVENT

This theme looks at how participants manage the life event, referring to their perception of parenting a child with DS in the following sections: general parenting experience up to now; how they view their role as father of a child with DS; and, supporting other fathers by sharing lessons they learnt on their own journey. In line with findings from a similar study (Takataya et al, 2016), participants experienced increased confidence as time went by; they had a clearer perspective of their role as father, and they had an improved image of both the syndrome and their child. Helen Keller poignantly summarised this state when she said, "When one door of happiness closes, another opens; but often we look so long at the closed door that we do not see the one which has been opened for us" (Keller, 2000).

5.2.4.1 Parenting experience of his child with Down syndrome

In line with previous studies (Skotko et al, 2011; Van Riper, 2007), findings of this study suggested a close relationship between participants and their child with DS. The narratives of participants provided persuasive evidence of participants' deep love for their child and immense pride in their child's accomplishments. Participants cited that through the parenting experience of their child with DS they learnt lessons in acceptance, flexibility and patience; they learned to be more kind, empathetic and tolerant; and, furthermore, participants noted a change in perspective on what is important in life. Celebration,

closeness, love, joy and laughter were frequently mentioned as an integral part of their experience with their child with DS.

I love to take her with me wherever I go. There is no greater feeling than having her in my life.

My child laughs more than others, is happy almost all of the time, he is smarter and tougher than you think but also more sensitive than you think.

Perceived lessons on **self-growth** were chief among the responses of participants, described as follows:

My life before my son was empty...chasing something and honestly did not know what. Life with my son has made me fearless...pushing harder to succeed.

I learnt not to live in denial and be honest about my child's condition.

This is a journey of self-discovery. Only after my son passed away did I realise what a positive influence he had on my life. He gave me real purpose. He gave two ordinary people an opportunity to do extraordinary things...he made us 'special' parents. He made us laugh and cry just like any other child. But he really really made us live. Life without him seems 'diluted'.

Some participants described how their experience taught them **lessons in patience**:

I learnt to forgive people their ignorance - I remember there was a time when I was just like them.

My son has a way of taking the scenic route...this takes extra effort and patience but the destination is worthwhile!

Corresponding to section 5.2.1.2, one participant commented on coming to a **greater understanding of love**:

When he was born we thought he would bring us down, but he actually elevated us. It's about having the right mind-set and trying to learn from the experience and to enjoy the unconditional love that comes from having a child with DS.

Some participants learned how to **advocate**:

I learnt to speak openly about DS and not try to hide it away.

I try to create awareness through dialogue... try to get people to change their perspective.

Don't wait for societal systems – create them yourself if you need to.

I take my child to sport games (rugby and cricket) where he can be part of the crowd...

Other participants learned to set **higher expectations** for their child:

I have witnessed my son exceeding every expectation in every area, in every possible way. I further realised that books and people tend to put limits on our DS children. I know he was born to surprise and to set new boundaries.

Take him to gym with me even if he struggles to do it like 'normal' kids do.

Only one participant indicated that his experience impacted him negatively, which may imply that the father had not yet reached a place of acceptance. As a result of becoming the father of a child with DS, he perceived a general change in his demeanour which he described as follows:

I did change in general...I am now more serious about life...I think I lost my sense of humour.

5.2.4.2 Role as father of a child with Down syndrome

Participant narratives offered valuable insight into what they perceived as their primary role as father of their child with DS. In line with the roles of the father (See Chapter Two), participants embraced characteristics of their fathering role to include protection, nurturing, loving, teaching, providing and guiding.

Protect and nurture

My role is firstly to protect him and love him, as with any other child... important that he grows up knowing that we love him and accept him exactly as he is...He must know that I delight in him, that in my eyes he is everything I could wish for in a son, and that I have confidence in who he is and his abilities.

Love and nurture

My role as a father...to love her as much as possible and to let her know how precious she is...I need to encourage her, praise her, and give her unconditional love and attention.

Love and teach

...to be a loving father to him...to expose him to society, e.g. take with to shops, movies, sports matches children's play facilities etc. so that he can observe what other kids do & follow their example. ...to play with him, especially physical games, e.g. wrestling, ball games, swimming...to give him guidance re. things that boys do...to encourage him to do things for himself and not to wait until someone does it for him, e.g. putting on clothes, do his own daily toilet, play on children's playground equipment, read books, take care of a pet, swim, etc.

Love and provide

...role as father does not differ from child to child, my role as father is to provide and love.

Protect and provide

I see myself as a protector and provider.

Guide, friend and role model

...exactly the same as my role for raising my other son...provider, protector, spiritual guide and friend

Provider, guardian, teacher, advisor, friend, role model.

To give him guidance re things that boys like... to encourage him to do things for himself and not to wait until someone does it for him...

5.2.4.3 Moving forward: supporting other fathers

Participants were asked an open-ended question about how their fathering experience could have been enhanced or influenced to be a more positive experience and in this regard, what advice they would offer to other fathers of a child with DS. A high correspondence was noted between their responses about perceived life lessons and their role as father of a child with DS as communicated in the previous sections. Some of the contributions will be offered as recommendations in the following chapter. However, it appeared that valuable lessons that fathers wished to share were related to a positive view of the future, and the value and benefit of reliable information regarding DS.

One participant acknowledges the challenge and recommended that, if expectations remained constant and realistic, all would be well. He stated:

... not to live in denial...be realistic...not to try and put too much pressure on the child to achieve or on yourself...To take every day, one step at a time. It will be okay...

Other participants encouraged fathers to gain knowledge and information and, in time, to pass their knowledge and experience on to new fathers. They commented:

For me it is already a positive experience. I only wish that information was readily accessible about the professionals who work with such kids in our neighbourhood.

...knowledge...sharing information of others who have walked this path. It is always beneficial to befriend other families with Downs Syndrome children to learn what they have done and to learn from.

5.3. CONCLUSION

From the findings it became clear that all participants viewed the diagnosis process and early years as particularly challenging; more so because guidance, advice and knowledgeable support was not readily available. This made most fathers doubt their ability to be effective parents and made them vulnerable and fearful of the future. It appears that this study dispelled the postulation that fathers are less likely to disclose their inner experience (West, 1998; Dindia & Allen, 1992) as participants in this study responded in an unguarded and sincere manner, demonstrating an open willingness to share experiences and deeper emotions.

This chapter reported on the responses of eleven fathers of children with DS. Rather than accepting the mothers' accounts of fathers' perceptions and experiences, this research attempted to redress omissions from other studies to explore the reality of what the experience is like for fathers of children with DS. One father reflected that he perceived this as a cathartic process, as he had not been given the opportunity to reflect in such depth on this issue. The father said: *Ek moet vir jou sê, dit was vir my goed... laat mens so bietje dink oor waar jy is op hierdie pad en hoe jy nou regtig voel.*

(Translation: *This I must tell you, this it was good for me...it makes a person think about where you are on this journey and how you actually feel about it*).

The responses of participants were consistent with past experiences of the researcher in this field. Firstly, that fathers all have fears and anxieties about being effective fathers for their child with DS; second, fathers experience similarities regarding diagnosis distress and concerns about the future of their child; and, last, fathers are unique individuals with individual and unique personalities and as such, a one-size-fits-all-sit-in-a-circle support initiative will not serve all in the same way.

It was clear that the time of diagnosis is often a critical turning point for parents, and a father's initial reaction may strongly affect how he and the other members of the family view the challenge going forward. Raising a differently abled child can trigger a variety of stresses for the father including a lack of information about the child's condition, uncertainty about the child's future, increased financial burden, the need to feel 'normal', and lack of support systems. However, from the responses of participants, fathers appeared to adapt well over time to parenting a child with special needs.

Fathers acknowledged that their child may never be able to reach full independence, and this knowledge changes the nature of the parent-child relationship. There was a sense that fathers understand that their responsibilities and duties may be long-term and that he will for the longest time have to contend with the demands of a child. This includes the core concern about their child's situation once they pass which starts incubating within the first overwhelming spell after the shattering diagnosis which shadows a father's thoughts day and night.

Parenting a differently abled child guides one to find joy in unexpected places, and to praise the seemingly unremarkable. From the feedback of participants, it was noted that, despite the gradual progress, fathers appreciated and recognised their child's accomplishment within the context of his or her ability. Participant responses also made it clear that parenting a child with DS is often tough love in motion, combined with compassion and patience.

Chapter Five offered the analysis and interpretation of the generated data. Chapter Six will present the implications, recommendations and conclusions of this study.

CHAPTER SIX

IMPLICATIONS, RECOMMENDATIONS AND CONCLUSIONS

6.1. INTRODUCTION

Chapter Six is the chapter where all different aspects of this research study culminates and the researcher decides whether the aim and objectives were met. This final chapter therefore consists of the discussion of the implications, and recommendations deduced from the research findings, as well as conclusions. It also includes a discussion of the limitations of the study, and some suggestions for further research.

6.2. DELIMITATIONS OF THE STUDY

The purpose of this study was to investigate, through a qualitative approach, the perspectives of South African fathers of a child with DS. This study was exploratory, descriptive and interpretative in nature the research topic was chosen to investigate, for the first time, the perspectives of South African fathers of a child with DS. Research on the subject of fathers and DS has mostly been restricted to the mothers or to limited comparisons of parent responses across different disabilities (Pisula, 2007; Ricci & Hodapp, 2003).

There is a growing body of literature that recognises the significance of fatherhood related to issues of disability, yet remarkably little research has been carried out specifically with fathers of children with DS. The intention of the researcher was to make a modest contribution to the field of DS research by advancing the understanding of the perspectives of South African fathers of children with DS and to encourage a more positive experience for fathers of children with DS, in future.

Overall, the study by Cuskelly et al (2008) offered probably the most comprehensive empirical analysis of what is currently known about families of children with DS. In addition, seminal studies in this area are the work of Skotko et al (2011), and most recently, Takataya and colleagues' investigation of the perceptions and feelings of Japanese fathers, conducted in 2016.

Examination of the narratives provided by participants, presented in the previous chapter, clearly reported various factors which contributed to their perspective of being the father of

a child with DS. The main objectives of this study were to establish how the fatherhood perceptions, perspectives and experiences of South African fathers of a child with DS impacted their parenting experience; what challenges these fathers experienced; how they perceived the personal implication of being the father of a child with DS; and, to investigate whether an effective platform of support would contribute toward an enriched fathering experience. An objective was to be able to make recommendations to fathers of children with DS based on the findings of this research study. However, issues which arose from the findings necessitated recommendations to further expand to the medical fraternity. A separate list of practical guidelines for fathers will be presented in Addendum D, which also includes guidelines for the medical fraternity and the community.

The study has many limitations and there are several avenues that can be pursued for further research on this topic which will be discussed later in this chapter.

6.3. MAIN CONCLUSIONS

From the narratives presented in the previous chapter and, as described by Takataya et al (2016) and Skotko et al (2011), the following aspects significantly influenced the perspectives of South African fathers of a child with DS. These are:

- Fathers experienced significant distress at the diagnosis and early days after the birth of their child, which added to their parental stress;
- Fathers were able to form strong attachments with their child and recognised the positive influence of the child;
- Fathers' experiences of support contributed either negatively or positively toward their perspective of this unique fatherhood experience;
- Fathers experienced an increased awareness of self-growth after having a child with DS and, based upon their own experience of support, feel competent to offer valuable guidance to other fathers of children with DS.

6.4. GENERAL OVERVIEW ON IMPLICATIONS AND RECOMMENDATIONS

Detailed conclusions are generally presented under each of the themes which developed during the analysis. However, given the overlap between specific themes and the significant findings of this study, the researcher has, after careful consideration, chosen to collapse theme three (collective experience of support) into theme one (intra-personal experience of this life event) and theme two (inter-personal experiences of the father) for the purpose of discussion of implications and recommendations. This decision minimized

replication and allowed meaningful integration of relevant aspects pertaining to support. For example, the inter-personal experience of the spousal relationship was found to be linked to the reciprocal support provided between the mother and the father. Another example was that the father's experience with support from the medical fraternity was closely related to his intra-personal experience of this life event.

As brief reminder, four themes developed from the participants' feedback. Theme One dealt with the factors that significantly influence the emotional, cognitive, physical, behavioural and spiritual subsystems of the father especially during the diagnosis stage and in his shift toward embracing the diagnosis (acceptance). Theme Two focussed on the various relationships which comprised the most significant relationships for the father at that time. Theme Three considered the fathers' experiences of support; and Theme Four looked at the way in which the father managed this life event, his perception of this parenting experience, and ways in which he sees the way going forward.

6.4.1. THEME ONE: INTRA-PERSONAL EXPERIENCE OF THIS LIFE EVENT

Theme One responds to the research questions related to the perceptions, perspectives and experiences of fathers, as well as some of the challenges presented to them.

Implications

It must be considered that fathers' support needs may be different, because by implication they may have a different experience from mothers (and indeed from other family members), as suggested by McDonald, Hastings and Fitzsimons (2010: 28). According to Hastings (2008: 318), there is no sophisticated understanding of precisely how to best offer effective psychological support to fathers. Hence, because negative appraisal and negative thinking have been shown to predict father psychological distress and lower self-esteem (Trute, Hierbert-Murphy & Levine, 2007: 8), conservative coping strategies related to paternal psychological well-being are offered, as also recommended by Glidden et al (2006). Recommendations stem from the researcher's personal experience as well as suggestions from the literature. These recommendations support problem focused coping, which has been associated with more positive well-being as well as relationship adjustment with partners (Stoneman & Gavidia-Payne, 2006), as opposed to avoidant coping strategies which has been associated with increased psychological distress for fathers (Hastings et al, 2005).

Whilst previous studies (related to parents or fathers of children with ID) have cited stressors to include social exclusion, lack of social support, and a partner who has considerable own emotional needs (Emerson, Hatton & Llewellyn, 2006; White & Hastings 2004), in this study stressors mostly related to financial concerns (present and future); adequate support; and, social adaptability of their child related to self-efficacy in terms of fitting into society.

Added to this, paternal cognitions have also been found to be related to fathers' psychological distress (Singer et al, 2007: 365). McDonald et al (2010: 35) argue that multiple stresses do not necessarily translate into a lack of appropriate parenting knowledge or skills; however, it is possible that fathers' psychological resources may be directed towards, or drained by, other life stresses. Internalised stress may cause the father to find it challenging to focus adequate attention on his child(ren) and may cause over-general and overly-negative cognitions about his child (or the DS diagnosis); that in turn, drives paternal well-being, ineffective parenting and/or a negative perspective of the fathering experience. Evidence in Singer et al's (2007: 366) meta-analysis of interventions for parental distress based on principles of cognitive behaviour therapy pointed to this being more effective if cognitive behaviour interventions also incorporated parent behavioural training.

The evidence of this study suggests that whether the diagnosis was disclosed before or after the birth of the child, all fathers experienced diagnosis distress, marked by feelings ranging from shock and disbelief to emotional dissociation, from uncertainty and denial to guilt, fear and anger. Interpretation of the findings of this study confirmed the exceptional distress associated with the diagnosis of a child (Pelchat et al, 2003: 232). Fathers often appeared to conceal emotional distress at this time, with the implication that they may reach a point where they internalize a perceived incapacity to respond to their child's specific needs at that time, and in future, which supports findings of Pelchat et al (2003: 233).

In line with findings by Takataya et al (2016: 7), many of the fathers in this study had a negative image of differently abled people, which, coupled with their ignorance about the condition and negative experiences with their doctors, compounded their immediate concerns and their fears for the future of their new-born child. Immediate concerns related to the health and well-being of the child and the father's own emotional needs at the time was superseded by the emotional needs of his immediate family. By implication, denial of his emotions translates to denial of the reality of the diagnosis. This form of self-deception

is in line with Kahane and Cavender (2006: 132) and provides the father with a temporary survival benefit to reduce immediate stress in order to buy him time to gain clarity and act more effectively. Thus denial serves as a temporary protection mechanism to stop the father from feeling overwhelmed and to assist the mind to process very difficult information (Naseef, 2001: 40).

Fathers need accurate and most recent information about DS. Because of the shock that comes with the disclosure of bad news, anything that is said afterwards is most often not properly internalised, therefore clinicians need to provide accurate information about family life when a member has DS (Skotko et al, 2011: 2346). Based on feedback, extensive training to the relevant healthcare professionals is needed in this regard. A 2005 American-based survey of 2500 medical school deans, students and residency directors revealed that 81% of medical students did not receive any clinical training about persons with intellectual disabilities, and 58% of medical school deans did not consider such training as a priority (Skotko et al, 2011: 2346).

In a similar survey in 2008, results showed that 45% of participants rated the training regarding pre-natal diagnosis as non-existent or barely adequate and only 36% felt that they were well qualified in general prenatal genetic counselling of a mother expecting a child with DS. Due to the high incidence of dissatisfaction with the treatment and information fathers received from the medical fraternity, the researcher has included recommendations for healthcare professionals. More practical recommendations in this regard are also offered in Addendum D.

The stages of the process of grief provided some way of understanding the tumult and disarray of the father's feelings especially at the time of diagnosis. Evident from feedback, these emotions do not impact everyone the same: while some fathers experienced one feeling at a time, others experienced many simultaneously. Also evident was that these feelings revisited fathers at different points, for example when they (later) inadvertently compared their child with typically developing peers, the sense of loss of dreams and 'what could have been' surfaced. The implication is that at such times, the father is confronted with the difference between the reality and 'what could have been' and the sadness resurfaces again as episodic grief, for the father to revisit the emotions yet again.

This study raises the possibility that emotional dissociation serves a similar purpose at the time of the diagnosis. In line with Orphan (2004: 101), fathers referred to states of 'mental paralysis' at the time of the diagnosis disclosure *"I was just numb... kept nodding while she*

was speaking..”, and by describing their feelings of disconnect from reality with terminology like “unreal”, “surreal” and “I thought I was dreaming and that I would soon wake up and find this not to be true.” A possible implication of emotional dissociation is that it disconnects the father and provides him fleeting latitude to think thoughts that would under normal circumstances be completely inappropriate at the birth of your child “I remember thinking if he died in NICU I would mourn him, but then at least we could go back to who we were as a family...more than anything I just wanted things to be how they were before he was born” and “I wanted him to somehow disappear or miraculously be cured.”

Every father has a dream for his child and when he realizes that those dreams are not going to come true, it can be devastating. By implication, the disappointment or pain is not singular; it may span a considerable time (“*You have a child with DS much longer in your arms and for life in your home*”). Some of the issues emerging from the findings related specifically to the fathers’ stress regarding the social acceptability of their child confirms findings by Keller and Honig (2004). This held an implication for the father and the child. For the father, the long-term commitment of having a child in the house, and for the child, possibly the diminished opportunity of independent living in future.

With the exception of one, all the fathers experienced anger, which, like denial, is an automatic response that offers short-term protection from emotional trauma (Dowling et al, 2004: 47). The implication of anxiety and feelings of helplessness is that it may result in anger about a situation that the father feels he has no control over. Fathers directed anger ‘out there’ as a self-protective action. The implication of their disappointment and grief was anger aimed in different directions for different reasons. This included anger at the universe, anger at God, anger at a wife (for insisting on having another child, who turned out to have DS), anger at friends and family for not providing adequate support, anger at society for offensive reactions, and anger at the doctors (for simply being the bearer of the diagnosis or for their lack of sensitivity while doing so).

Resorting to anger implies that the father did not have to experience guilt, and beyond this, the distress of fear, hurt and powerlessness (Stelzer, 2013). This finding has important implications for developing guidelines for fathers as well as healthcare practitioners; for fathers, to know that it is a normal post-traumatic stress reaction to experience arbitrary bouts of anger (however misdirected), and for health practitioners to be more sensitive to the emotional trauma of the parents during pre-natal, post-natal or diagnosis disclosure consults. Recommendations in this regards are provided in Addendum D.

The evidence of this study suggest that fathers tend to be harsh self-critics. Impacting every subsystem, the implication of self-criticism is that it fuels the manifestation of guilt, anger and other emotions of the father. Thus, some fathers berated themselves for not coping, not knowing enough, not spending enough time, not doing enough, and so forth. The implication of such anger is that it can be very isolating and lead to a spiral of negativity. For some fathers, this potentially debilitating emotion was directed toward the diagnosis (and by proxy the child who brought 'imperfection' into the family and is now threatening the 'security' of the family), which can be seen as part of processing something which seems to make no sense to him at all (*"The dreams and prospects of raising a regular boy were destroyed"; "I felt that DS had come and destroyed our family"*).

Only one participant pertinently associated shame with his child with DS (*"I was even a bit embarrassed to let anyone see her...Maybe I felt a bit guilty for whatever reason and maybe I thought that people would judge me by her situation"*). The implication of shame is that it is an intense emotion that may make the father feel 'exposed' and therefore wanting to 'cover up'; and as such it is sometimes confused with guilt (Orphan, 2004: 102). This was implied by fathers' reactions of defensiveness toward others who wanted to claim this event as a tragedy; wanting to attack healthcare practitioners for simply delivering the diagnosis; pretending that everything is fine; withdrawing from their spouse and friends (safety cocooning) or by reproaching themselves for not being able to 'fix' this situation. At times, fathers may do all of these. However, it is also possible that the implication of shame may be the first sign that a father has actually begun to accept that their child is differently abled, and thus, it serves the father more than denial.

The implication of a fathers' lack of knowledge and ignorance about DS was that it fuelled their apprehension about an unknown and unclear future, especially in light of the political climate and lack of support for the differently abled in South Africa. Fathers asked these questions: *"What happens to my child once he has finished his school years?"* ; *"Will he be able to live a life of supported independence?"* and, more perplexing, *"What will happen to my child when I am no longer here?"* These issues and others related to the deficiency in government support of the differently abled in South Africa and how it impacts families, calls for further investigation.

By implication the financial burden of a differently abled child is alarming and impacts the father on every subsystem, especially the physical. The added financial pressure may impact the father logistically in the following ways: he may be forced to continue working for much longer than anticipated in order to provide indefinitely for the child with DS; he

may need to take on additional work to cover costs; he may have to increase insurance policies, medical aid contributions and so forth; and, he may have to provide accommodation for the child into adulthood and beyond, thereby having to maintain an appropriate sized property for longer than anticipated.

By implication this specific life event presents stress related to the past (diagnosis disclosure stress), as well as present (day to day challenges presented by the diagnosis), and stress about the future of the child (and family). Participant responses were consistent with PTS, which implies that the father may have experienced feelings, physical behaviours and actions related to PTS. An implication of PTS is possible increased alcohol consumption, which may point to avoidance behaviour or a form of escapism that distracts the father from the reality of his child's diagnosis and the effect thereof on his child and indeed his entire family. Similarly, exaggerated interest in sport (noted by a father) or other outside activities may indicate escapism behaviour. PTS influences every subsystem of the father and the implication may present as ongoing psychological problems if not attended, as recommended by Swartz et al (2011: 379).

Similarly, the implication of a positive perception associated with being the father of a child with DS, as described by every participant of this study and confirms similar research findings (Takataya et al, 2016; Skotko et al, 2011; Cuskelly et al, 2008; Blacher & Baker, 2007), clearly indicated a high correspondence between their experience of joy and happiness and the love that they have for their child. Fathers cited lessons in patience, tolerance, selflessness, understanding, flexibility, and acceptance. They referred to an increased sense of purpose and priorities; responsibility; personal growth and strength; and, increased spirituality. They learned to be more empathetic, kind, loving and less judgemental. A combination of these findings provides some support for the conceptual premise that acceptance of their child's diagnosis leads to an improved emotional state.

The willingness of fathers to embrace the difference and acknowledge the abilities and strengths of their child appeared to supersede challenges of the child's functional activities (for example speaking, grooming, communicating and so forth) and were not predictors for how much pride and love was felt by the father. In line with findings by Skotko et al (2011: 2342) all fathers responded that they love their child and are proud of their accomplishments. It can be assumed that the improvement in the emotional state (as precursor to acceptance) was facilitated by fathers' increase in knowledge about DS. It was clear that as fathers expanded their knowledge about DS, they experienced increased confidence and parenting competence, which supports findings of Takataya et

al (2016) and Muggli et al (2009). This corresponds with the fathers' increased recognition of the positive influence of the child, his own paradigm shift about disability and more specifically DS, and his acceptance of his child and the diagnosis. Fathers appeared to gain information primarily from the internet, whilst their wife, and other parents of a child with DS, were secondary sources of information.

The researcher believes that the fathers' reference of to the nebulous 'bond' between parents of children with DS ("*...it's as if we belong to the same club*"), as well as the reference a participant made to how he 'stalked' a family with a child with DS through a store, coupled with the expressed need of to speak to someone who has walked this road before, implies fathers' need for normalcy within an unexpected and unanticipated situation. From this it seems that combined with a positive attitude, fathers try (day by day) to change the meaning that they initially ascribed to this life event. Perhaps this is part of embracing the difference. And perhaps it is fathers' way of confirming the DS 'advantage' that the reader will recall was referred to in section 3.4.3. Significantly, fathers of this study accept their child as a person first, and the diagnosis as secondary.

Acceptance of the diagnosis does not imply the absence of pain and fathers are aware of recurrent sadness that seems to recur from time to time. The researcher believes that acceptance is about letting go of preconceived ideas regarding the child (the hopes and dreams of what could have been), the diagnosis (undeniably forever a part of the reality) and of how one sees one's life turning out. Thus, acceptance is a *decision* and not a *feeling*. Seen in this light, perhaps acceptance brings both release and relief for the father; so that it is possible for him to replace preconceived notions about his child and the child's future (and his own together with his child) with *new* hopes, *new* dreams and new plans for the future with his child. In other words, the realisation that he has landed in Holland; and that this destination holds its own spectacular magnificence.

Clear from the fathers' responses was the implication that acceptance lifted the burden of the diagnosis and fathers were able to start looking at the world differently, appreciate their other children even more and shift their value system, and, discover renewed spiritual wisdom ("*... completely changed my way of thinking and experiencing life...*").

In our society which appears to be obsessively-ambitious, functions at incredible speeds, and is primarily outcome driven, a father marvelled at how his child with DS provides the 'gift of slowness' as described by Mason (2001: 21); just simply being, living, doing in their own time, at their own pace. Thus, as the feedback showed, the implication is that the

father reassesses his cognitive, physical, behavioural and spiritual paradigms, as he is often required to rethink his life goals, the pace of pursuit thereof, and the cost of both. Based on the findings, the following recommendations are suggested to support the emotional well-being of the father at the time of the diagnosis and after.

Recommendations

Recommendations for healthcare professionals

The following recommendations serve as guide for practical application that may be followed by healthcare professionals in order to facilitate a more gentle approach to diagnosis disclosure for parents.

- It is recommended that an information packet be developed for all parents who receive a pre-natal or postnatal diagnosis of DS that provides a balanced view (highlighting both positives and negatives) of the effect of the syndrome as well as family life that includes a child with DS. This study provides further information that can be incorporated into informational booklets, public awareness campaigns and professional training sessions.
- It is recommended that practice guidelines be written for healthcare professionals on how best to deliver a prenatal or post-natal diagnosis of DS (Skotko, 2011: 2346). This study provides evidence-based information from the sampled population that can be shared with couples during parents' prenatal counselling (or prenatal parenting classes) and/or during (or after) the diagnosis disclosure.
- It is recommended that public awareness campaigns be initiated to educate pre-pregnant couples about life with DS. Best practice stories from parents of children with DS as well as significant research findings should be incorporated to provide a balanced description of the syndrome and family life which includes a person with DS.
- It is recommended that quality training material be developed for healthcare professionals on how to deliver a pre-natal and post-natal diagnosis of DS as suggested by Skotko et al (2011: 2346).
- It is recommended that quality training material be developed which provides a balanced perspective on what to expect from the child and family life after the diagnosis of DS for inclusion in ante-natal parenting classes at hospitals and private institutions.

Recommendations for fathers

- It is recommended that fathers attend traditional cognitive-behavioural based interventions and behavioural parent training, as also suggested by Singer et al (2007: 365).
- Acceptance and Commitment Training (ACT) also merits investigation as a potentially effective psychological intervention for fathers of children with developmental disabilities as suggested by Hayes, Luoma, Bond, Masuda and Lillis (2006: 21).
- Mindfulness-based parenting interventions related to children with developmental disabilities have also demonstrated positive results (Singh et al, 2006: 175). Increased involvement has been displayed by fathers who apply present-centred attention when parenting their child with ID (MacDonald & Hastings, 2010b: 237). Mindfulness-based interventions support present-centred attention (which means the father stays with his perceived aversive emotions rather than seeking to escape them). In this regard, Siegel (2010: 3) suggests that being present (mindful) helps develop focus, resourcefulness, and perspective that support the father as an individual, and aids in his process of dealing with his child. Focus here refers to self-reflection which facilitates self-awareness as a starting point for social and emotional intelligence required in dealing with the diagnosis of a child.

Being fully present in life supports the challenging pursuit of parenting a child with DS, especially because the child tends to do everything slower. So, rather than do things *for* the child (thereby facilitating assisted helplessness), Siegel (2010) suggests that the father stays present in the moment (even when aversive emotions arise), and allow the child to do things for himself or experience new things for himself. This may be as simple as brushing own teeth. The father may find that many teachable moments arise from staying present. Being mindful may further provide the resourcefulness to pursue parenting this child with more efficacy and more resilience.

- It is recommended that, as a starting place, a matter-of-factly perspective (similar to an outsider trying to create order) stands the father in good stead when he comes to realise that he needs to face, feel and express his feelings (Orphan, 2004: 106). Bottling up feelings expends much energy which could be put to better use dealing with life and the situation in a constructive way. Physical activity of any kind is conducive to emotional release. Unexpressed feelings will manifest in physical

symptoms such as being run down, anxious and stressed, blood pressure conditions, illness, sleep disturbances and so forth (Orphan, 2004: 107). The following suggestions by Potter (2014: 472-488) is recommended as strategies to cope with stress. These strategies refer to the alternative method to coping with stress, in which one works to minimize anxiety and stress in a preventative manner. If the father works towards coping with stress daily, the feeling of stress and the ways in which he deals with it as the external event arises becomes less of a burden.

Suggested strategies to improve stress management include:

- Regular exercise – set up a fitness program, 3–4 times a week
 - Support systems – to listen, offer advice, and support each other
 - Time management – develop an organizational system
 - Guided imagery and visualization – create a relaxing state of mind
 - Progressive muscle relaxation – loosen tense muscle groups
 - Assertiveness training – work on effective communication
 - Journal writing – express true emotion, self-reflection
 - Stress management in the workplace – organize a new system, switch tasks to reduce own stress.
- Individual counselling or therapy: Working through grief will take time and may be marked by periods of great sadness and heart-wrenching grief, as well as anger at himself, his spouse, doctors, God or anyone else he feels has let him down. The father who gets stuck in the grief process may find himself in a deep depression from which he would seemingly be unable to find a way out. It may be preferable to solicit the services of a trained counsellor to gently facilitate this process. It is imperative to the father's emotional health to help him deal with stress effectively, and to recognize the link between stress and fear, anxiety and depression. It is therefore advisable to seek trauma counselling to prevent dissociation to escalate into mental health problems.

Counselling will also help the father to face his own fears and to monitor it so that he can manage his anxiety effectively and have a prevention plan for relapse (Nejad & Volny, 2008: 18). At this stage, professional counselling and even medication, if needed, are recommended in order to help him regain equilibrium in all the domains again. Once the father has reached acceptance, counselling may further direct him to reframe the life event on a cognitive level in order for him to have hope, and to develop strategies to turn this into a positive experience. This is imperative for the father to reach an acceptable level of quality of life for himself, for his child with DS, as well as for the rest of the family.

- It is recommended that fathers manage their anxiety. It does not take long for most fathers to become aware that they, not some professional, are their child's medical, educational, and therapy managers, even though they may have minimal knowledge of these areas. Fathers should avoid relying on alcohol or medication as a 'solution' to the 'problem'. These solutions will keep the father from changing and may just make matters worse for all concerned. Realities should be faced, stressful as they might be. Helpful techniques to help a father deal with anxiety may include: deep breathing exercises; meditation; relaxation activities such as listening to music; reading; enjoying a hobby; exercising several times a week (even just a walk); and, if this is within the father's regular scope of activities, even regular church attendance and daily prayer may result in lower blood pressure and better coping.
- In terms of planning for the future, it is recommended to enlist the help of a financial planner to secure sound investments and sensible policies for the child with DS (and siblings for future reference should they become the guardian of their sibling with DS) and to update their will. It may be worthwhile for the father to familiarize himself with the terms and conditions of the government financial grant for persons with disabilities. Fathers should become cognizant on the restrictions and allowances of their medical aid (such as chronic benefits which include physiotherapy and so forth). Suitable guardians need therefore to be appointed.

6.4.2. THEME TWO: INTERPERSONAL EXPERIENCES OF THE FATHER

This theme responds to a secondary objective of this research pertaining to the personal implication of being the father of a child with DS, and looks at the different relationships of the father.

- **Relationship to self**

Implications

A sense of ruptured self, resulting from the disruption that the diagnosis brought into their life may present the father with an obscured view of their previously 'perfect worlds' (*"DS had destroyed our family...sad, ugly picture of who we were as family...happy and beautiful didn't fit with who we were now..."*). The implication may be that some fathers experience a dip in self-esteem, because they feel that their image (and self-image) may have been tarnished by this event.

Smith and Mackie (2007: 107) simplify self-esteem as your reputation with yourself; in other words, that which you have come to believe about yourself over time. A low self-esteem implies that you have built up a bad reputation with yourself; if you have high self-esteem, you have built up a good reputation with yourself. A practical implication is that a father's healthy self-esteem is likely to spill over into his behaviour toward others (especially his child with DS and the family members). Thus it has the ability to positively (or negatively) influence how he views his role as father. If he views it as positive, the pay-off is an improved fathering experience, or not. A healthy self-esteem does not assert his right to do whatever he wants whenever he wants; rather, it reminds him that he is fine, no matter what experience may be occurring in his life at any given time (Neff, 2014).

The father who is overly concerned about what other people think, how they see his family and how they are acting or reacting to him is likely stuck in self-image. Focusing on self-image presents problems that may influence a negative mind-set in the following ways: the father who is determined to win the approval or admiration of others is certain to experience frustration and unhappiness; the father who surrounds himself with people who believe that surface level and transient elements are vitally important to quality of life will be let down by those who do not approve of his differently abled child; the father of a child with DS cannot consider leading a life of comparison, especially when he compares the progress and performance of his child with DS to typically developing children of others. The implication of a focus on the external world of self-image may result in him experiencing dissatisfaction with who he is, and who his child is (Neff, 2014).

A further implication of the perceived 'disruption' by the father is that has the ability to generate an internal shift. In this study, noteworthy shifts related to fathers' expectations of love (from unconditional to loving without expectation); and to loving which encompasses forgiveness. Fathers also noted a shift away from the expectation imposed by others. The implication may be that, as noted by participants, fathers learned to take nothing for granted. Such shift in the expectations of their child also implies the realisation of acceptance; hence, that no milestone is small – each one deserves to be celebrated. In line also with findings by Takataya et al (2016: 7), that such a shift in attitude and a sense of value supports the father's confidence in his fathering ability.

Recommendations for fathers

- A vital component in a healthy relationship to self includes a healthy self-concept; the base of which is a healthy self-esteem. Carter-Scott (2000: 12) invites fathers to include respect, kindness, caring, and integrity in their relationship to self. Fathers should remember that self-image is related to needs that are based on fear. Seeking outward approval or attempting to control, is acting in fear, which is based on the idea that he is not good enough. Until the father does not find peace within himself, it will never go away. In contrast, the father who lives his life with a high degree of self-esteem is resilient enough to acknowledge the life event for what it is yet remain connected to his deepest internal being. It is recommended that fathers realise that they do not need to justify their worth; that they can let go of expectations (imposed by others or by themselves); and, that they need to get to know themselves, which includes taking time to try different things to figure out what they really enjoy, as a self-nurture exercise (Schacter, Gilbert & Wegner, 2009).
- **Spousal relationship**

Implications

A practical implication of fathers' understanding of the individuality of the 'grieving' process is that it may facilitate an increased closeness between husband and wife. To reinforce such positive repositioning of this relationship, fathers specifically referred to the cohesion between them ("facing it together"), "a new dimension of trust" between them, and "improved patience" with each other. We can infer from this that an improved spousal relationship may also spill over into increased involvement with the child which leads to increased confidence in parenting the child with DS, and ultimately positively affect the perspective of the father regarding this fathering experience. Although most fathers experienced a closer spousal relationship at this time, some fathers needed time to process the diagnosis on their own time and their own terms. This may imply that some fathers require more time to reach a place of acceptance of the diagnosis of their child.

In terms of limited time spent with each other due to imposed physical demands of the child with DS, the implication may be distance between some couples. From the feedback it can be assumed that uncertainty about how to raise a baby with special needs may cause one (or both) parents to over-compensate with intensified, time-consuming therapies; or that taking on additional work-load to increase income; or attention to siblings, may all add to limited together time for parents. If these reactions go

on over a protracted period, negative patterns can appear and continued demands directly or indirectly related to the child can swamp the spousal relationship (Orphan, 2004: 115). The implication of physical and emotional exhaustion may include issues such as distance between parents, resentment, or, apathy toward each other. Improved spousal relationships as recorded in this study, supports stronger spousal bonds and thus strengthen the position of the family as a whole; which supports an enhanced parenting experience and perspective of this role.

Recommendations for fathers

- Orphan (2004: 120) recommends that couples put their relationship first. It is possible that a sense of cohesion may increase their ability to deal with the uncertainty of this situation. Mutual support and meaningful communication (for example confiding in each other, sharing concerns about their child's future, planning together, crying together, and reaching solutions together) are vital components to refocused commitment to each other and the future with their child. As mentioned, this is established by communicating one's needs, concerns, feelings and anxieties. Talking through issues, lead to joint, sound decisions, and sharing the feelings of grief shares the burden. In this regard, research has also shown that when the father gets involved with hands-on parenting, he relieves the mother's caretaking burden and stress by participating in tasks and providing emotional support. "It was found that mothers' satisfaction with fathers' help, not the actual amount of help provided, predicted both mothers' and fathers' marital adjustment" (Cuskelly et al, 2008: 107).
- Couples therapy is recommended in cases of communication difficulties, dissatisfaction with the emotional relationship, or problems in co-parenting. Even if no solution is found per se, a therapist may help them to repair conflict, help them to cope with the difficulties together, and guide them to an understanding and acceptance (Tartakovsky, 2016).
- **Father's relationship to siblings**

Implications

A father who is mindful of maintaining balance between the needs of all of his children will increase his involvement in their lives. This may result in increased knowledge of the strengths and weakness of each child and may further increase his empathy with the child with DS and the siblings. In this regard, participants expressed improved gratitude for their typically developing child and acknowledged the uniqueness of their children.

Although increased involvement improves the father-child relationships, a measure of frustration may arise from challenging issues surrounding social outings for fathers who view this as limited due to the child with DS. The implication of unequal division of time between siblings may be possible sibling rivalry and resentment toward the child with DS.

However, corresponding to the findings of Skotko and colleagues (2011) who found that the majority of parents noted a good relationship between siblings, every father in this study believed that siblings were more protective, kind, caring, helpful and loving toward their brother or sister with DS. The relationship between father and siblings and between the siblings and the child with DS was uniformly described as positive. It is likely that positive relationships between siblings also support a positive overall fathering experience (Cuskelly & Gunn, 2006).

Recommendations for fathers

- As suggested by Meyer (1986a), just like their parents, siblings need balanced and accurate information about DS and the way it affects their brother or sister. The father, as preparer and principled guide, should provide information and set the example of how to treat their sibling with DS and others with disabilities. As a sounding board, the father should therefore create the space and opportunities for siblings to talk about their feelings, negative emotions and resentment in order to achieve a greater understanding and acceptance. By adopting a mindfulness approach, that father in this way provides skills to help them deal with conflicts that may arise because of their sibling's disability.
- Buckley (2002) recommends the following: It is important that the father recognise the needs of his child with DS as well as needs of siblings and encourage them to develop individual identities, to affirm their individual positive qualities, and to teach them to support and encourage each other. This may be facilitated by creating an emotionally safe place at home that will encourage his child with DS and siblings to share anxieties and concerns, hurts and disappointments. In dealing with both the child with DS and siblings, the father should be consistent in boundaries, rules and acceptable behaviour toward each other. Both children should be encouraged toward independence and simple problem solving. Making any child over-dependent on others will damage their self-confidence. Both parents should caution against imposing too much responsibility related to 'training' or 'preparing' the sibling to take care of the child with DS. Essentially this is a sibling and not a surrogate relationship.

- Prior to bringing the baby home, sibling preparation should be a priority. Both parents (not just the mother), should explain to the sibling with the greatest diplomacy and circumspection, on their level of understanding, the implications of having a differently abled sibling. Provide simplistic answers to questions and caution against overload. Such a session should be informal yet planned without interruption. Not only does this inform siblings adequately, but remaining calm, positive and pro-active also serves to alleviate much of the internal stress of both parents and siblings at this time.
- **Father's relationship to friends and family**

As there are numerous correlations between the relationship to friends and family, the researcher has elected to combine the implications and recommendations.

Implications

The relationships with friends and family provide invaluable emotional and physical support to the father (Skotko & Bedia, 2005). Both negative and positive experiences regarding support from friends and family were reported by participants. One issue that emerged from the findings were that, although one father experienced unmet expectations of certain friendships, fathers were generally supported by their friends in varying degrees. The implication of positive friendship support is that the father has someone he can talk to, share his fears and concerns with and who at the same time normalises the situation for him by hearing about how other fathers deal with similar situations.

Related to reports that some fathers noted a shrink in their social circle, these findings raised intriguing questions regarding the nature and extent of support from friends at this time. Is the social circle shrinking because the father has come more selective and critical of the people he now let into his life? How do friends know what are appropriate reactions to the diagnosis? Do fathers expect them to sympathise, apologise or say nothing? What kind of help does the father expect from friends? How should friends refer to the child? How do friends and family approach the parents for information? The list goes on. The researcher believes that discomfort and ignorance about disability in general and DS specifically, may impact a relationship and the implication is that, rather than offend the parents in any way, friends may choose to withdraw in the interim.

Another implication of unmet expectations of friendship may be that for most people this may be a first experience with DS, and although the intention may be towards sensitivity, ignorance on the 'etiquette' of disability may be lacking, even to those close to the father.

It is likely that friendships (or relationships) that were not substantial to start off with may disintegrate altogether.

Often the development of new friendships (with people they have more in common with, such as a child with DS) compensates for the estrangement from unsupportive friends. An implication of fathers placed high value on interactions with other families of children with DS, which is in line with other research findings (Skotko et al, 2016; Cuskelly et al, 2008). In this study, interactions with other families of children with DS without fail provided fathers with the most valuable information about DS. This had a positive influence on their perspective of families, family life and children with DS.

Recommendations for fathers

- The father who knows the diagnosis beforehand is in a perfect position to empower himself, friends and family with valuable information to dispel fears and myths regarding DS. An informal 'meeting' may create a perfect opportunity to talk about these issues. Should the father feel that such a meeting may be too emotionally taxing, drawing up a simple informative note may be an alternative option to be forwarded to friends and family prior to the 'meet-and-greet' tea (or distributed at the function and informally discussed as a starting point). The help of a parent who has already been in a similar situation may be elicited if the father feels too emotionally vulnerable; this option provides an opportunity for informative discourse facilitated by a knowledgeable, impartial third party.
- It is recommended that the father communicates openly and honestly with close friends in order to minimize his own stress and to dispel the pretence of being 'okay'.
- Interactions with other fathers in similar situations are recommended to regain a sense of normalcy of the situation (Orphan, 2004: 119).
- Engaging in usual social activities are recommended as this alleviates the father's stress and forges strong, supportive friendship bonds.

6.4.3. THEME THREE: COLLECTIVE EXPERIENCE OF DOWN SYNDROME

This theme responded to the research objectives regarding challenges presented to fathers of a child with DS. As mentioned earlier, aspects related to this theme was

integrated into Theme One and Theme Two due to its relevance and significance to those themes as follows: the father's perception of support from the medical fraternity was integrated into Theme One as these primarily influenced his intra-psychic functioning; and, the perception of support from his wife and from other parents of children with DS was integrated with Theme Two as it relates more to the issue of inter-personal relationships.

In the following section we look at fathers' perception of educational institutions as well as their perspectives on support groups.

- **Educational institutions**

Implications

Fathers in this study mentioned that they tended to leave most decisions regarding the education of their child to the mother. The implication is that their information is inevitably 'second-hand', and may rob them of the opportunity to become empowered and be able to advocate to their child (and others with DS). In this regard, fathers appeared to share a common concern regarding suitable schools for their child with DS, and how to access these. This implies that a cognitive shift is required toward active involvement as opposed to merely an 'outsider' concerned perspective. Whilst ignorance of the educational rights of their child perpetuates fears around the schooling situation, information generally puts these fears into perspective.

A more pro-active role in the education of his child implies the father's involvement which extends to decisions related to the future of his child in terms of possible employment and thus eventually fulfilling a contributory position in society. In this way, through his active involvement, the father empowers himself, his child with DS and in effect the whole family unit. Moreover, as reported in this study, the informed, empowered father is able to take a pro-active stand and make a difference.

Recommendations for fathers

- It is recommended that fathers gain independent advice regarding the rights of his child to education (as opposed to relying in the mother for information), and that he should familiarise himself with the structures which are in place to support his child's educational needs. This may include anyone from a therapist regarding speech therapy, for example, to the local Education Board regarding schooling options for either inclusive or special schooling, to the DSSA governing body, or the closest Down syndrome Association chairperson. Other parents of children with DS are invaluable

reference resources. A father who is aware of the options is in a better position to take informed decisions and become actively involved in his child's educational journey.

- Pro-active fathers generally acquire extensive knowledge about research, literature and effective interventions for their child with DS through their own research, attending conferences provided by lead specialists in this field, and through parent support networks. This level of knowledge is frequently not matched by the educators of children who have DS. This lack of awareness of key information erodes parents' confidence in professionals.
- It is recommended that the father facilitate an information session at prospective schools in order to 'educate the educators' on DS, how it effects the child, the child's learning profile and other significant information to create an awareness of the abilities and capabilities of children with DS. Such training should be provided to the whole school staff prior to the child starting school. Most mainstream schools will have no experience of supporting a child with DS and typically staff in special schools has no or little training in the specific profile associated with DS and recommended intervention.
- It is advisable that, for mainstream schools, training should also cover benefits and aims of mainstream inclusion and be provided by a knowledgeable professional with education background. Educators are likely to welcome a father's perspective and such involvement may extend also to the father providing information to other parents (fathers) from this platform. In this way the father can provide valuable guidance and constantly update and upgrade his own information regarding these issues.
- **Support groups**

Implications

Fathers had different thoughts about support groups and the benefit thereof. However, the majority of participants showed an interest in the establishment of a chapter especially for fathers. In this respect, Blacher and Baker (2007: 342) suggest that it is vital to present a platform that supports the father as an individual system, as part of a couple system, and as a parent. The emotional responses in every subsystem of the father's individual system are antecedents to his adaptation to new life circumstances as the

father of a child with DS. By implication, a platform for focussed father support may fulfil the role of supporting the father as individual to develop his own skills and resources, and also serve as mediator toward positive psychological adaptation to the experience of being the father of a child with DS together with fathers who are in the same situation.

Recommendations for fathers

- In keeping with the suggestion of Rhodes (2003: 59), a chapter for fathers may provide a space for fathers who understand, yet continue to grow toward a deeper understanding of their situation; would guide each other to gain insight into causes of conflict and stress; assist in developing new and more effective ways of interacting and communicating; learn how to respond to stressful events; and mostly, how to avoid becoming stuck in negative patterns of interaction. Whilst a chapter for fathers will primarily provide a space where fathers can share their experiences in an informal setting, it is recommended that occasional guest speakers will address topics of their choosing, or issues as they arise. Such a chapter will also create an opportunity to involve the grandfathers and other male role players in the child (and father's life). Research has shown that fathers expressly prefer to be supported by people who have direct experience of being a father (parent) of a child with DS (Takataya et al, 2016; Skotko et al, 2011).
- The researcher's precise aspiration is to facilitate a chapter for fathers which may provide a realistic space where fathers can talk about how they feel; where they can process what is happening at home and work out how to change some things; where they can go where they are recognized and encouraged as a person; in essence a space where they can just talk man to man and father to father, to ultimately develop a network of support that may encourage increased parent wellness, which includes a close relationship with his child with DS.
- Addendum C provides comprehensive guidelines for starting a chapter for fathers.

6.4.4. THEME FOUR: MANAGING THE LIFE EVENT

Due to the clear correspondence between the implications and recommendations of the parenting experience and the role of the father of a child with DS, the researcher has elected to combine these aspects. This theme addresses the research objectives related

to how fathers perceive their role as father of a child with DS and also what they perceive as valuable advices for other fathers of children with DS.

- **Parenting experience of his child with Down syndrome**

Implications

Findings of this study unequivocally support a positive parenting experience of fathers in terms of a close, loving relationship between father and child. The parenting experiences of fathers have also been discussed in section 6.4.1. However, the implication of a positive parenting experience is that it may provide the father with a clearer view of the future with his child, and a solid base on which to build their relationship. Implications of the positive fathering experience was described as increased self-growth, positive life lessons referring to an enhanced understanding of love, the ability to advocate on their child's behalf and also set higher expectations for their child with DS. The implication of the previous point is that the father does not decide what the ceiling is for his child's potential, but allows the child to explore and expand and set his own ceiling.

The implication for a father, who prepares for his role through education and training in child development, parenting skills and the particular needs of his child, is that he will naturally be more comfortable in his role as father. In turn, the child may experience a sense of comfort and assurance and know unequivocally that his/her father is actively involved in raising him/her. On the other hand, the father who lacks confidence in his child rearing abilities may be inclined to be less involved in his parenting role.

The attitude of the mother may be a major contributor to the father's involvement. Her level of maturity and her ability to hand over the reins will encourage the father's participation. It is important that the mother communicates her knowledge of child development and the needs of their child, and encourages the father to expand his own knowledge base. By implication, the father who is confident in his role and has the opportunity to actively participate in this task will *want* to spend optimal time with his child, which has only positive outcomes also for the child with DS. Only one participant indicated a negative perspective of this fathering experience, which may imply that he has not yet reached a place of acceptance.

Through their love and care, fathers leave a permanent imprint on their children's lives. The implication of the father's protecting, nurturing, loving, teaching and providing roles may provide him with a sense of fulfilment and thus support a positive perspective of his

fathering role. By also being a decent role model for his child, the father may provide adequate guidance to their children in order to make their own way in the world, whether the child has an extra chromosome or not.

Recommendations for fathers

- Parenting skills can be acquired informally by reading books, internet articles or by attending parenting workshops. Two examples of typical parent training programmes are: The Stepping Stones Triple P (SSTP) is a behaviourally oriented program which consists of learning and positive reinforcement procedures (Plant & Sanders, 2007); and, the Webster-Stratton Incredible Years program has been widely adopted for typically developing pre-schoolers with behaviour problems and has been adapted for parents whose children have developmental delays. This program consists of developmental and behaviourally oriented methods to teach parents to engage in appropriate play, and methods such as praise, limit setting, and reinforcement to establish acceptable social behaviour and to treat challenging behaviours (McIntyre, 2008: 1177; Reid, Webster-Stratton & Hammond, 2007: 607).
- To gain sound information on the development of their children, it is recommended that fathers read the manuals of Curriculum for Infants and Toddlers with Special Needs (CCITSN), based on young children with DS and works toward developmental gains of the child (Del Giudice, Titomanilo, Brogna, Bonaccorso, Romano & Mansi, 2006: 51). There is much information about parent training available on the internet varying from group to individual parent training, manuals, curriculums, video and live instruction. All of these variations play an important role in effective parent training, and are cost effective ways of becoming knowledgeable.
- The following recommendations were extrapolated from Parachin's (2008) 'Seven habits of highly effective fathers': (1) Negotiate flexible working hours in order to accompany the mother to the child's therapies and appointments, or even at times when the mother is feeling overwhelmed; furthermore, become involved in your child's development by attending parenting workshops (the internet may be a resource to seek information regarding such opportunities); (2) Taking their role of spiritual teacher and mentor seriously and lead by example. Outside of his family unit, such an example may include acts of benevolence to those less fortunate. A father who engages in spiritual guidance for his child provides an invaluable resource for leading with life's many challenges; (3) A highly effective father does not hesitate to shower

his child with physical expressions of love such as hugs, holding hands, kisses, assisting him/her with physically challenging moves and so forth (this may also include treats and small tokens of his affection for his child); (4) It is important to spend alone time with your child with DS in order to observe your child, sense his dreams and hopes (no matter how simplistic), and then encourage him/her to pursue those goals. For a child with DS such a goal may be to ride a bike. Or attempt the high slide on the playground. Or hit a golf ball. An effective father has learnt that confidence is the companion to success and he will do whatever it takes to instil confidence in his child; (5) A good father identifies teachable moments and uses every opportunity to teach the child new skills. In this regard it is recommended that the father simplifies lesson, and to even use the child's natural propensity for self-talk to affirm the lesson, no matter how cliché it may sound to an outsider. This method soon becomes habit for the child when he/she repeats the lesson while doing it. For example, teach your child how to tie shoe laces, or pack his/her own lunch, or feed the pets, and so forth; (6) One of the most important things a father can do for his child is to apologise when he has been insensitive, unkind or unnecessarily impatient; (7) Be a father your child can count on by being consistently dependable, trustworthy and reliable. A father with a sound moral compass and who is reasonable sends the clear message to his child: 'You can count on me: win, lose or tie.'

- **Supporting Other Fathers: Moving Forward**

Implications

Every participant agreed that the advice of other fathers of children with DS would have been invaluable to them especially at the time of diagnosis and during the early days of uncertainty and apprehension. It can therefore be implied that fathers participating in this study placed a high value on the input of fathers who have already gone through some of the stages of parenting their child with DS, as also found by Takataya et al (2016) and Skotko et al (2011). The implication of such support is that it may alleviate feelings of isolation and provide a sense of solidarity for fathers of a child with DS. Furthermore, it may also result in fathers regaining a sense of self as they reaffirm their commitment to their role and garner valuable information to set them on this journey.

Recommendations

As recommendations for fathers of children with DS, the researcher has elected to offer the advice of the experts: the fathers who participated in this study. Their authentic responses, garnered from the question: *Relevant to your journey with your child with DS,*

what advice and/or insight that you which had been shared with you, would you now offer to a new father of a child with DS? The researcher believes there is no better way to respond to the research questions than to let the voice of the fathers be heard as recommendations to this section. Often most loudly expressed by what they are *not* saying, these ‘lessons’ (either learnt by fathers, or they wished they had learnt earlier) support every preceding word of this study. *This* is what fathers *wish* they had known before... implying that *this* is what was (or still may be) lacking in *their* experience as a father of a child with DS.

The responses of fathers (in original format with no changes) range from poignant to pragmatic. The researcher offers a concise precis (indicated in bold) preceding the individual responses of the fathers.

Recommendations from fathers to fathers

- **Maintain a healthy perspective:** *Perspective. Be patient, don't forecast future, seek well-meaning advice, remember that your child is unique and will have their own individual experience.*
- **Avoid becoming over-analytical or anxious – your child will sense this immediately and it may lead to increased frustration for yourself and your child:**
Do what you can do regarding the physical care and for later in life for your child, but take every day one day at a time, because we tend to overreact and run away with things even before it happens. Enjoy and love that little baby, you owe it to yourself and to the baby. Raise the child just as you would do with any other “normal” child. To be sensitive towards any impairment there could be but never jump the gun. I strongly believe that you should always first try the “normal”: way of doing things with your DS child before rushing into some rehabilitation program that might not be necessary and will put unnecessary pressure on yourself and your child.
- **Learn to distil the advice you will be so generously given. Try to cross reference and compare sources. As a parent of any child, rely on your basic parental intuition (gut feel) and work from there:**
The advice would vary depending on the personality of the dad and his emotional state. I would be careful of using phrases like, “special children are born to special parents” and “God would not give you a challenge you could not carry.” I heard this many times and because the terms were clichés they carried no real value. In general, I would tell them the truth. The child will really test his character and give him an opportunity to become a very special father and

husband. I would tell him that this child will fundamentally change him for the better - we don't learn or grow from "easy". I would tell them that when my son was born I also battled to accept him. But now that I have experienced having a child with DS and lost him to cancer, I would still choose a life with him (and relive the whole experience all over again) because it is so unique in so many ways. The child will give him a sense of real purpose and pride that you won't find anywhere else. It will be a tough life, but if handled in a positive way, it will be a very rich life.

- **Be prepared to be amazed by the abilities that your child is likely to develop, more so than the anticipation of failure that you may have originally predicted. Encourage, praise, stimulate, regroup and persist. It will pay more dividends than you can possibly imagine:**

In my experience, a DS child will exceed all that you can ever imagine – everyday – all of the time.

- **Be patient with the ignorant, supportive to the floundering and forgive the insensitivity of those who inevitably wish to provide advice from an external perspective:**

Don't underestimate your spouse's need for support, especially when tough trials are being gone through. Some days you just have to accept life as it rolls and it's not possible to change everything. Forgive people for their ignorance - remember there was a time when you were just like them.

- **Impart your knowledge gained through experience and contribute from your position of knowledge to the brave soul who writes such a book. The more varied the experiences and knowledge presented in such a publication, the higher the value of the future parents of children with DS:**

A book must be written so that new parents, grandparents, other family members and friends can get accurate information as to what needs to be done immediately and how their journeys with their new child can be influenced to ensure a good Objective for them and the child. They must be advised of potential short and long term problems they might encounter so that they can better prepare themselves rather than be reactive.

- **Remember that your Heavenly Father will never send you a cross to bear that you and He cannot carry. Believe, pray, persist:**

Each child is God's gift. Love and cherish your child.

- **Anticipate and prepare to be taken on a journey you have not planned for. Be excited by the uncertainty and changes in direction as your child grows and you grow with him/her:**

Everything looks uncertain now, but remember, Down syndrome does not define who your child is. 46 Chromosomes are just him, only 1 is DS. Get to know him, see him grow and find out who he is, what makes him smile. And you are going to meet the most amazing people on this journey!

- **One of the biggest problems with understanding DS is ignorance of the masses, as well as the hesitance of parents to encourage integration of children with DS into the daily routines and social interactions that we pursue. Your parental duty is to educate and to carefully expose your child with DS to the world outside of their home, with all the experiences that they may come to face in their lives. It will enhance their understanding of themselves and provide them with confidence to rise to the challenges before them more readily:**

These kids live 'in the moment' – when they engage with you, enjoy those moments with them. They are able to do more for themselves than we think they can, constantly encourage them to do so. Be aware that, although they might sometimes seem to be oblivious of what is going on around them, they do pick up on what is going on – albeit somewhat slower than 'normal' kids. They also watch you as a parent closely and will do things the way that you do – so be careful what you say & do in front of them. They are very loving and kind hearted children – treasure it! Also, take them to rugby, cricket, etc. games where they can be part of the crowd to cheer their teams on and just enjoy an outing together with a large crowd. Take them with you to gym and do sports activities with them – even if they struggle to do it like 'normal' kids do. Seek advice & guidance from other parents that have raised kids with DS & apply it in the development of your own child. Don't wait for societal systems - create them if you need to.

- **Encourage your child every opportunity to develop, grow and understand the world of the average person in society. Initiate, integrate, participate, appreciate – help your child to stand their ground:**

Nothing will change in your life. Every child with Down syndrome is unique, the same way as with normal children. Treat your child different sometimes, it is better to push your child harder to reach his milestones. It is all about loving your child.

- **Try to stay calm, think, breathe. Your child will be more beholden to your stability, patience and guidance than any other. It is vital that you maintain perspective and pace yourself into the parental responsibility that is an integral part of any parent – even more so of a parent of a child with DS:**

You have to be grounded and stable through the ups and downs. The journey can be very emotional but you have to keep everyone together through the tough times. You have to keep being positive and share that positive energy. You have to be supportive and help where you can. You need to know your spouse really well. If you sense they are battling then you need to let them talk and vent. If we were battling then we would share this and try and come up with a way to make things a bit better. Sometimes [my wife] did not want an answer – she just wanted to talk. I needed to understand that. In [my son's] later years we battled to interact with him from an educational perspective (puzzles, books, toys etc...) so we were financially lucky enough to get help from occupational therapists, speech therapists, aqua tots, school etc... to support us in that educational role. We provided the love and the hugs but relied on others for the development side. In hindsight this may have been a mistake. Maybe education mixed with love would have been better for him. But I also think that we had to admit to our shortcomings and instead of trying to frustrate ourselves with that side of things (which would have been a negative experience) we relied on the help of others. I also think that as a father (aside from the day to day support), you need to have a plan for the future for the child. With the increased life expectancy of a child with DS, it is likely that they will outlive their parents. They need a safe place to stay and enough capital invested to support them (i.e. through a trust) for the rest of their lives.

- **As best you can, be supportive, understanding, patient and strong for each other. Anticipate and prepare for the challenges of the life journey and be excited and elated on the easier 'down'hill slopes. Hold hands, hold faith, hold forth. You are not alone:**

It's not an easy road for any parent. Along the way we have to lift each other partners up to be the best parent(s) we can possibly be for our children. We have to constantly mentally motivate each other as a parent. Reach out to other parents that is new to the DS family or that might be expecting a child with DS. Just be yourself, and love your child unconditionally! It's not an easy life journey, but it's worth it!

6.5. LIMITATIONS OF THIS RESEARCH STUDY

Although a concerted effort was made to conduct a well-planned and thorough investigation, the following practical and methodological problems surfaced during this study.

This study was subject to selection bias as majority of participants came from Gauteng and sampling criteria denoted correspondence in socio-economic status. A more comprehensive study would include not only participants from other provinces, but also from rural areas in order to provide a broader spectrum of perspectives of fathers with

children with DS. Furthermore, results were limited by the lack of diversity of participants, as only one black South African father participated.

The small sample resulted in limited evidence of the perspectives of fathers. The sample characteristics excluded many diverse fathering situations that are prevalent in South Africa, including single fathers, divorced fathers, gay fathers, absent fathers (who work away from home), unemployed fathers and fathers representing various cultural groups. As such, a very partial picture of the perspectives of fathers of children with DS was presented and eliminated the possibility of giving full consideration to the perspectives of these fathers. The research would have been more relevant if a wider range of perspectives had been explored especially in terms of the experiences of rural and socio-economic challenges. It is essential that the results of this study be compared with a similar study which includes the aforementioned groups and from other provinces in South Africa. Therefore, the findings of this research cannot be generalised, that is, confirmed that the same or similar findings would emerge from another sample group in a different setting.

Participants provided their narratives guided by a questionnaire. Although helpful in guiding the responses, a small number of participants restricted their responses to succinct information, while others provided multiple pages of comprehensive data. It would have been useful to conduct personal interviews to investigate the perspectives of fathers as participants would have been able to comment, justify and substantiate their responses or to provide respondent validation of the researcher's interpretations. This would have reduced the potential for error as well as provide insights from alternate perspectives. However, self-reports of participants in response to questionnaires made it possible to target topics relevant to the analysis. All participants showed preference to employ self-reports as this provided them with time to reflect upon and formulate their responses in their own time and using their own language to tell their 'story'.

Clearly defined open-ended questions extricated relevant information, whereas interviews or focus groups may have been intimidating for participants who are less likely to be forthcoming with responses. This assumption is based on judgement of the length and quality of some of the written responses. Whilst self-reports provided participants the opportunity to reflect on their responses, a limitation may be that this also influences a tendency to present themselves in socially desirable ways. This would result in bias in findings. The researcher appealed to fathers during the initial interview to answer the open-ended questions honestly and openly, reminding them of the benefit of authentic

and truthful contribution to this study. Especially to the benefit of fathers who will in future be in their position.

A limitation of using TA was that the data were coded and themes identified in the data by one person and the analysis was then discussed with a supervisor. The peer check did involve a measure of comparison, however, not all the data were controlled in in this check. Hence, the TA process allowed for consistency in the method but it failed to provide multiple perspectives from a variety of people with differing expertise. The researcher agrees with Fereday and Muir-Cochrane (2006: 45) that should this method be used for another similar study, the coding of data could involve several individuals with themes' being developed using discussions with other researchers, and/or the participants themselves.

Despite the above-mentioned factors the researcher is satisfied that the goals of this research study has been met and trusts that a significant step has been taken in the understanding of the perspectives of South African fathers of a child with DS. As a result, the researcher believes that findings can provide sufficient information to create a greater awareness of the perspectives of fathers amongst parents, the medical fraternity, educators and the broader South African society.

6.6. SUGGESTIONS FOR FUTURE RESEARCH

While scrutinizing the data, the researcher identified an overlap between the phenomenological study and instrumental case study. Whilst the phenomenological study explores and describes the lived experience of a phenomenon for several individuals, the instrumental case study aims to explore and describe a particular situation that several individuals may share (Tlou, 2006: 39). Through this lens the researcher identified several possible topics for future research. One particular topic, experienced by too many families crossing paths with the researcher over twelve years, for an instrumental case study (situated within the larger context of families of children with DS) could focus on how parents deal with the unspeakable tragedy of losing a child with DS, as the effects of such loss has not yet been closely examined. This suggestion was also encouraged by the content and level of quality of the response submitted by the participant who had lost his child.

The researcher is aware of ongoing research in the field of DS, especially in the UK, USA and Europe. Although there has been an increase in the number of studies which include

fathers, to date very few studies have investigated the association between the parental experiences of fathers of younger children with DS versus adult children with DS. Whilst some research has been carried out on fatherhood perspectives and experiences of Black South Africans, no studies have been found which shed light on the shared attitudes, values, beliefs, and practises, patterns of interaction, perspectives and experiences of fathers of children with DS, the nature of which remains unclear within this group.

The singular aim of this research was to define the perspectives of fathers who have children with DS, as a start. Future research is needed to investigate the experiences of fathers of children who not only have a diagnosis of DS, but who also present other physical challenges, in other words a child with multiple disabilities. Such a study may predict both potentially negative and potentially positive outcomes, and thus facilitate the development of appropriate family interventions to support fathers in this situation.

Inasmuch as the attitudes of parents who have children with DS are captured, further attempts should be made to capture the attitudes of parents who chose not to continue their pregnancies after receiving a prenatal diagnosis of DS. A comparative study between perspectives of mothers and fathers may yield interesting results as this is a decision that frequently confronts parents. Such a study would be highly sensitive, and to date only one such study has been performed in the US (Korenromp, Page-Christiaens & van den Bout, 2007).

Very little is known about twins with DS. The researcher was rather disappointed when an increased workload prevented a particular father from participating in this study. This father presents with a significant challenge: he has twin daughters, one born *with* DS and the other born *without*. A case study of such an exceptional situation could add significantly to the body of knowledge regarding the perspective and experiences of a father in this situation. Especially related to episodic grief, such a unique situation presents a dichotomy of enormous proportions for the father, especially in terms of the ambiguity of grieving one life and celebrating the other when both children are alive. While causal factors leading to this occurrence remain speculative, the knowledge gained from such a study could provide valuable insight into this phenomenon, of which there is only a handful worldwide.

Given that fatherhood is an emerging field of research, more prospective studies need to be conducted on the quality of fathering experiences, the types of effective interventions for fathers, and the different needs of fathers across cultures. This should not be

restricted to fathers of children with DS, but should also include fathers of children with other challenges, especially rare diagnoses. Overall, programs, policies, and research need to reflect diverse fatherhood experiences, as they allow us to understand the ways in which culturally specific parenting practices are beneficial to young children, and early childhood development.

Finally, most studies in the field of DS have only been carried out in a small number of areas. Longitudinal studies are needed to understand transitions in the lives of fathers who have a child with DS tracking the experience of the father with his child from birth to early intervention, from middle childhood to adolescence, and the challenging time from adolescence to adulthood) with the expectation that studies which include fathers with exceptional circumstances may add exceptional value to the current body of knowledge regarding fathers of a child with DS.

6.7. FINAL CONCLUSION

This chapter discusses the implications based on the findings and presents recommendations not only to fathers, but also to the medical fraternity. Limitations of this study and suggestions for further research have been discussed and answers to the question: “So what about the results obtained in this research study?” The four themes that were identified by means of the data analysis formed the basis for answering the primary research question.

Based upon the findings, recommendations that could be applicable to fathers (many of which can also be related to friends and family members) were presented. Primarily this research hopes to extend the knowledge of fathers of children with DS and the following conclusions can be drawn from this study: the intra- and inter-personal experiences of the father, as well as the support he receives and provides, significantly influences his perspective of this life event and how he navigates it going forward. In response to a secondary research question, this study is significant in that it has several practical applications offered as recommendations. These recommendations are expanded to more practical guidelines in Addendums C and D. The addendums provide additional information pertaining to piloting a unique chapter for fathers for who wish to join such an initiative, and secondly, it offers additional practical recommendations for families with a differently abled child.

This study was a cognitive shift toward providing support for fathers, guiding them to navigate a pathway to a successful future with their families and their child with DS, empowering them to an elusive level of self-sustained ability to provide the family with a sound and stable leader figure who is capable and able to stand tall in the face of all probable circumstances which may arise from having a child with DS and all the complexities this may present. The researcher made a modest attempt to contribute to the understanding of the perceptions of South African fathers of a child with DS and how this impacts their fathering experience, and feels confident that the objectives of this study was adequately met.

The issue under this research microscope is not definitive. My objective was not cast upon a black or white outcome, but rather to render a glimpse of joy in the vividly colourful mosaic of possibility. This study is an exploration of striking possibility and potential. This thoroughly exciting possibility is embedded in the title of this writ: Exploring the fatherhood perspectives of South African fathers of a child diagnosed with DS. The intention was not to dismiss or invade or modify any of their experiences or perspectives, but ultimately to enrich, deepen and augment their fathering experience.

As a final thought, I wish to encourage fathers with these few words:

*Dearest father of an exceptional child, you are not expected, by the way, to be perfect at **any** of this. Just raise your awareness. Each shift in your energy will create markedly positive results. You have my word on that.*

I have however reserved the final inspiration to fathers for William Ernest Henley who penned this powerful message, Invictus:

INVICTUS

Out of the night that covers me,
Black as the pit from pole to pole,
I thank whatever gods may be,
For my unconquerable soul.

In the fell clutch of circumstance
I have not winced nor cried aloud.
Under the bludgeoning of chance
my head is bloody, but unbowed.

Beyond this place of wrath and tears
looms but the horror of the shade.
And yet the menace of the years
finds, and shall find, me unafraid.

It matters not how straight the gate,
How charged with punishments the scroll.

**I AM THE MASTER OF MY FATE:
I AM THE CAPTAIN OF MY SOUL.**

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ADDENDUM A

5 January 2015

Dear Participant father of child with Down syndrome

EXPLORING PERSPECTIVES OF SOUTH AFRICAN FATHERS OF A CHILD WITH DOWN SYNDROME

My name is Heidi Webber and I am currently studying towards a *Doctor Educationis* (Doctorate) at the Nelson Mandela Metropolitan University. As prerequisite of the degree, I am required to complete a research thesis. My study aims to create a chapter for fathers, guiding them to navigate a pathway of enrichment in the fathering experience of their child diagnosed with DS, within the general fatherhood landscape perimeters.

In order for the study to be a success, I require fathers of children with DS to participate in the research. I would be exceptionally grateful if you would consent to participating in my study.

Participation in this research involves responding in writing to questions in an interview guide aimed at your perception and experience of having a child with DS and how it has affected your life personally; the type of support you found lacking; and thoughts on the road already travelled, and going forward in your fathering experience. Hence, this is a self-reflective account of your journey thus far. You will be required to complete this assignment within one week or sooner as expedience thereof will maintain the focus of your account. Upon completion kindly return your reflection either by e-mail or I will collect it from you by prior arrangement.

Upon receipt of the responses, all names are replaced by a code and analysis of the generated data is done only once I have received *all* responses. I urge your candid and truthful response in order to validate the authenticity of this study. As a researcher I comply with all the ethical rules which govern this type of research and assure you of my deepest respect in handling your responses in a non-judgemental and confidential manner.

Participation is completely voluntary. **Confidentiality and anonymity** will be maintained at all times, both in the analysis of the data, and the completion of the Doctor Educationis. A summary report of the findings will be made available to the participants.

If you would like any further information or are unclear about anything, please feel free to contact me via e-mail: heidiwebber@mweb.co.za or telephonically on 083 442 5069.

Your cooperation and participation is valued and appreciated.

Kind regards

HEIDI WEBBER
Researcher

DR. A.J. GREYLING
Supervisor

ADDENDUM B

**EXPLORING PERSPECTIVES OF SOUTH AFRICAN FATHERS OF A CHILD
WITH DOWN SYNDROME**

Thank you for your participation. Your input is of *exceptional* value. Please be completely frank and honest in your response and use this document as a guide to your response. You may respond in the language of your choice. All information is **confidential** and will not be published. **INSTRUCTIONS:** **Section A:** please use the table as is. **Section B:** please follow the numbering (copy & paste questions onto a Word document and respond under each question); **Sections C to H:** Copy & paste onto same Word document and respond under each section. Please return your response as **one** complete document.

SECTION A: PARTICIPANT INFORMATION

NAME (Optional)	
AGE	
MARITAL STATUS; NUMBER OF YEARS MARRIED (If applicable mention 1 st , 2 nd marriage)	
AGE AT BIRTH OF CHILD WITH DS	
CURRENT AGE OF YOUR CHILD WITH DS	
EMPLOYMENT SECTOR	

SECTION B:

Elaborate as broadly and detailed as possible to the following open ended questions:

1. Regarding DS diagnosis: were you informed before or after the birth of your child?
2. Describe your experience of being told the diagnosis of your child. Please share your feelings, perceptions and reaction at that time
3. Describe your first thought/thoughts.
4. What were your immediate concerns?
5. What concerns do you have at present?
6. Did anyone support you at this time? Who and describe how?
7. Who would you generally confide in when you needed this type of support?
8. Looking back at that event, elaborate on what you think would have made your experience different, and explain how it might/could have been different.
9. Describe what sort of support you would you have liked to have access to at that time? Please elaborate
10. How did this event (having a child with DS) influence your relationship with your spouse, your other children and your friends?

SECTION C:

Describe the challenges **you** face/ have faced in parenting your child with DS? Please elaborate wherever possible and include the positive and negative aspects.

SECTION D:

Describe how being the father of a child with DS has affected you on the following levels? Please use the following headings and *elaborate comprehensively* on each:

- On an **emotional level**;
- on a **physical level** (e.g. in terms of having to provide/ having to take care of the child/ being a caregiver for the child/ putting measures in place for later in life, and so forth);
- on a **cognitive level** (have you gained any knowledge/understanding of DS/ how has it influenced your thinking about disability in general, and so forth);
- on a **behavioural level**;
- on a **spiritual level**

SECTION E:

In your opinion, and considering your journey up to now, *how* do you think the experience of being the father of a child with DS can be enhanced or influenced to be a positive experience? Please elaborate.

SECTION F:

Define *how* you see **your role** as father in raising your child with DS? Please elaborate.

SECTION G:

Relevant to your journey with your child with DS, what advice and/or insight that you wish had been shared with *you*, would you now offer to new dad of a child with DS?

SECTION H:

If a group specifically for fathers existed, would you join such a group? Explain your response. If *yes*, please elaborate on *what* such a group should offer to make it meaningful to *you*.

PLEASE FEEL FREE TO ADD ANY INFORMATION YOU DEEM APPLICABLE

YOUR TIME AND YOUR VALUABLE INPUT IS GREATLY APPRECIATED. THANK YOU.

Heidi Webber – Researcher (heidwebber@mweb.co.za)

ADDENDUM C

GUIDELINES FOR STARTING A CHAPTER FOR FATHERS

- **Introduction**

In 1998 West referred to the inclination of men to be less prone to engage in therapy, to attend family therapy, couples therapy, or to seek help for either physical or psychological problems. Across many studies (referred to throughout this thesis), it is clear that the majority of fathers experience distress about their child's diagnosis, and that some fathers subsequently also experience distress in relation to their parenting role. Furthermore, there is a tendency for fathers to be less likely than mothers to disclose their inner experience, so what is reported may not accurately reflect that which is experienced. As one participant in this study remarked "*I don't like bringing my private and personal feelings into the open, so I would need to feel safe in a place to share*".

In the following sections the researcher will present her motivation for the implementation of a chapter dedicated to the plight of fathers, as well as how she envisages piloting such a chapter. As this chapter will be for fathers, an appropriate starting point is the opinion of participants of this study regarding the character of such a chapter. Suggestions below are supported by direct italicized quotes from participants:

- **Fathers' opinions about the character of such a chapter**

- It was suggested by one father that the character of the chapter should not just offer "*sitting in a circle and everybody shares their feelings*" type support. This father suggested that the chapter needs to highlight "*that which is normal*" about their situation, and as such "*the environment and atmosphere needs to feel normal*". He suggested: "*Attending golf days, rugby games or going on weekend bush trips will set the scene for open discussion on DS.*" The idea is to focus on DS per se, but allow fathers the freedom to include general topics of discussion that may include sports and other interests.
- The focus should be on that which is positive about this life event.
- In similar vein, one father's opinion was that "*such a chapter would only be successful if it had a purpose beyond emotional support*". He felt that such a group should provide practical support to individuals and other families of children with DS who have specific needs at a specific time; thus, he felt that outreach work would be a positive spin-off for such a group. He believed that the support element should occur coincidentally, rather than intentionally.

- Guidance from other fathers of older children with DS may offer valuable advice through to each stage of development in order to prepare fathers of younger children for what to expect in future.
 - One father proposed that parents of older children with DS should be invited as guest speakers to offer advice and guidance regarding what is available for persons with DS in the workplace after they have left school. This father was very interested in the sustainability of full-time positions for adults with DS and felt that best practice stories from other parents would offer valuable guidance. In this regard, one of the researcher's aims for the chapter was to gradually compile a database of companies and positions suitable for and suited to the different needs of young adults with DS. The idea would be to permeate towards informal 'internships' with the future view of permanent placement within organizations. To this end, fathers would be motivated to become involved in recruiting possible companies to add to such a database.
 - More than one father felt that there need not primarily be a specifically intended positive pay-off when joining such a chapter. One of the opinions in this regard was: *"It doesn't matter what the group offers, it's just good for your soul to communicate with other fathers in the same boat and that face the same battles as you do."*
 - One father suggested that the other family members are also involved. However, because this chapter would be specifically for fathers, the focus here would be on fathers. The researcher does, however, plan to include different members of the family at different times for specific activities, as well as one annual inclusive event for the whole family.
- **Alternatives suggested by fathers**

The following alternatives were suggested by fathers:

- Some fathers indicated a preference to discuss their thoughts, experiences and feelings with a good trusted friend in a one-on-one situation. Each of these fathers mentioned that such an arrangement was better suited to their personality type, hence such a preference.
- One of the fathers said that he would prefer to see a therapist for one-on-one sessions if emotional support was required.

One father reported that his previous experiences with support groups were not positive; hence he was rather skeptical about the merit of a chapter specifically for fathers. He noted: *"Some people with children with DS make the situation about themselves and not*

about the child.” This father felt that he did not want to be singled out just because he has a child with DS, and although he would be interested in helping other fathers, he did not see any benefit in joining such a chapter. Another father was concerned that within a focused group, *“a victim mentality may develop”*.

The researcher believes that the person who drives such an initiative needs to be professional, problem-focused and offer a balanced perspective at all times in order to avoid this from happening. Also, although the researcher plans to pilot such a chapter, it would be ideal if a strong leader emerges from within the group to take lead. After all, the primary intention is to establish a group about fathers and for fathers.

- **Motivation for a chapter for fathers**

One of the fundamental motivations to pilot a chapter for fathers is that it may encourage men to see more clearly their value as fathers and thereby increase a sense of connectedness to and enhanced involvement with their child with DS. It is significant that fathers understand the role they play in promoting optimal development in their child with DS as recommended by Fox et al (2015: 471). To this end, much of the literature provided in the literature review chapters will be adapted for, and applied and incorporated into the chapter sessions.

The researcher believes that a balanced perspective of the father as head of his family facilitates a more accessible, manageable and relaxed journey with their child with DS. Therefore the researcher holds the view that enhancement of this specific experience of fathering is rooted in establishing a chapter specifically for fathers of children with DS. As an independent group, affiliation to DSSA will be discretionary.

Although the exact objective of the chapter is still to be formulated, the format will depend upon the needs of its participants. This chapter is not intended to be group therapy and does not stem from the opinion that fathers are incapable or not coping. Rather, the main aim is to enhance and ‘normalise’ the experience for fathers as much as possible. Because this is both an inexpensive and effective way to offer assistance to fathers, the researcher believes that it may in future become the preferred method of serving the needs of fathers in this specific situation.

Essentially, the aim of such a chapter is to provide a realistic space where fathers can talk about how they feel; where they can process what is happening at home and work out how to change some things; where they can go where they are recognized and

encouraged as a person; in essence, a space where they can just talk man to man and father to father without fear of judgement.

- **Purpose of a chapter for fathers**

For fathers who have a differently abled child, the distance between the idealized fathering experience and the actual one may be enormous (Murray et al, 1991: 225). Fathers have reported having less access to social support than mothers (Kayfitz, Gragg & Orr, 2010: 241). Therefore, creating a space where fathers are given respect for their role may serve as a support to their involvement with their child with DS (Altieri & von Kluge, 2009: 91). Sufficient support must be in place to help modulate their expectations and to experience success within the given situation. The findings of this study showed that fathers need other men in similar situations with whom they can discuss their concerns and a safe place to show emotions and brag about their children; a space where every milestone and achievement carries equal weight and is cause for celebration.

Such a chapter is tasked with a simple yet essential mission: to create a platform for fathers of children with DS to have the opportunity to empower, assist and support themselves and others, through fellowship and action, to promote positive awareness and celebrate individuals with DS. This chapter will play both an informative and a supportive role to facilitate timely resolution of possible stressors related to the experience of being the father of a child with DS.

- **Character of the chapter**

The group will consist of a manageable group of peers (fathers of children with DS of any age and gender). Initially the researcher will facilitate the meetings and attendance will be voluntary. The character of such a chapter will initially constitute a monthly dads-only programme within a non-judgemental safe space where fathers can talk about their experiences, share parenting strategies and draw on the best practices of others who understand and share the unique situation of having a child with DS.

Personal invitations will be sent to every participant of this study and will also be extended to the initial sample group. Thereafter members may invite other fathers to join. The first meeting will include an informal needs assessment and a programme for the year will be drawn up in collaboration with fathers. Fathers will be given an opportunity to make suggestions for monthly activities and these arrangements will be coordinated between the researcher and the participating father. Members of the chapter will receive the programme for the year and will be notified of the next meetings.

- **Structure of the chapter**

With the initial assistance of the researcher as facilitator, a typical meeting will be informal and follow the general tone set by the fathers for that meeting. To facilitate a flow of such a get-together, it may initially be necessary to structure 'pockets' of sharing information and knowledge, providing ample time for fathers to unburden, brag, share, release and reboot. The chapter will not be typical guest-speaker-monologue sessions. However, fathers will address pre-established discussion requests through the facilitator and balanced information will be provided and open discussion encouraged on these topics.

The initial 'pocket' would involve sharing recent experiences and observations (significant pointers which transpired during the preceding month). This will take place in a trust atmosphere where fathers feel comfortable talking about and working through very personal issues and experiences. Fathers will do the talking and come up with suggestions, whilst the researcher will merely facilitate and guide the discourse. The second 'pocket' will involve discussion points raised by fathers prior to the meeting. To this end, the researcher will offer researched, valid, relevant and balanced information in a personal and practically applicable way. This section will be inter-active, but will essentially be led by the facilitator. The third 'pocket' involves informal social discourse and will involve the fathers only.

- **Future vision for the chapter**

The chapter will also incorporate a quarterly one-day focused workshop offering new and relevant material on issues of parenting, fatherhood and the unique experience of being the father of a child with DS. Matthews and Hudson (2004: 78) emphasize that material included must be based on sound theoretical principles and evidence demonstrating effectiveness to the cause. This will be facilitated by the researcher and may include 'guests' such as other parents of children with DS, individuals with DS, or other relevant persons who can expand the knowledge and insight of fathers.

Once the first chapter is established, one of the fathers will step into this role, with the researcher only attending the second pocket of every session. Training for fathers who wish to start their own chapters will be a future goal. The goal is that there will be an expansion of chapters for fathers until all fathers have access to such a group experience, should they choose to join the intended network of support and guidance.

Once every quarter, a session will involve fathers and their children with DS. Activities will be planned according to the age of the children and activities may typically include

movement therapy, art activities, partnered games, and, action songs and dancing. Movement therapy will include a combination of yoga, Brain Gym and children's bio-kinetics. All the activities will be focused on the promotion of trust, interaction and confidence to overcome social and behavioural difficulties that may arise.

- **Communication**

Electronic media, such as WhatsApp, will be incorporated to keep in touch with group members. As men are generally resistant to overshare or lengthy discussion on electronic media, this medium will be employed purely as logistic communication method, reserving discussion and sharing for chapter meetings. Should the fathers indicate a need for such, a Facebook page can be created exclusively for this group. The chapter will essentially provide information and support (or a sounding board), thus the researcher will explore the demand for a weekly email anecdote to encourage cohesion of the group. Because feedback from the fathers will be essential to the development of the chapter, the researcher may request that fathers initially submit a short reflective letter after each session to serve as feedback and indicator of the success of the meeting.

- **Identity of the chapter**

As a suggestion, the researcher has come up with the name GODADS: Group of Dads Affirming Down Syndrome.

ADDENDUM D

PRACTICAL RECOMMENDATIONS:

FOR THE FATHER; MEDICAL FRATERNITY AND COMMUNITY

The following recommendations are of a more practical nature and are directed to the father. These recommendations are presented under the themes (and within the first two theses, have been apportioned to the subsystem of the father it is primarily most likely to affect). These recommendations have been compiled from a variety of sources, varying from workshop and conference notes, to blog entries, or notes taken from articles over a protracted period of twelve years; hence especially the first section is largely uncited. However, this does not diminish the value of these recommendations to the father. The advice may be applied or discarded; the choice remains that of the father.

THEME ONE: INTRA-PERSONAL EXPERIENCE OF THIS LIFE EVENT

Emotional subsystem:

- **Understanding your anger:** These recommendations were compiled from several workshop notes and blog entries over a protracted period.

Anger is one of many emotional reactions to the painful reality of an unexpected diagnosis; and as such, it must be recognised as a natural, human response. Although anger is not chosen, however, whether refuse to surrender it or to resolve it, is a choice. Anger has different roles which are important to recognise in order to work through it.

Anger is initially **protest**: an attempt to ward off a reality which seems too devastating to comprehend; and it is an attempt to undo an untimely and unwarranted life event. Although this phase of anger is the most acute, it must be expressed in order for it to burn out. Thus, the reality of the diagnosis must be acknowledged; it cannot be fought or denied.

Anger is a means of **retrieval**: The target may be anyone from the doctor, to God, to oneself, or even at the child who has just been diagnosed. Anger feeds the hope that somehow the diagnosis can be reversed. However, what must be accepted eventually is that the diagnosis is irreversible and it cannot be undone.

Anger is a means of **control**: As such it is an emotional response designed to regain control. It is a defence against the helplessness of being able to do anything about the diagnosis, and it must be vented and burned out before one's impotence can be accepted.

Anger can be expressed in a constructive or counter-productive way. Constructive expression leads toward some form of resolution or dissolution of anger, while counter-productive venting perpetuates, perhaps even magnifies, the effects of the diagnosis.

Constructive venting: This can include verbal and non-verbal means. It is important for fathers to have permission to verbalize their most intense feelings of anger, regardless of where the anger is targeted; even at God. It is also permissible to direct some anger at your spouse. Yelled or screamed expression is both therapeutic and healthy; however the caveat

may be to do this in the company of someone who is understanding and accepting of the father's need to verbalize the full intensity of his anger.

Non-verbal means of ventilating anger may include crying (especially intense, uncontrollable crying which is a means of releasing pain, helplessness and frustration); physical exercise (running, walking, golf, tennis – the more physically demanding the better as it forces deep physical release of anger).

Counter-productive ways of dealing with anger include: repressing anger; displacing it (blaming, being harsh, critical or cruel for no apparent reason - which may cause emotional isolation); excess use of alcohol or drugs; increased smoking or eating. In this case the father is his own target of the anger, and these actions may decrease his self-esteem and self-worth.

Individuals vary greatly in their expression and experience of anger; some erupt with little provocation while others are slow to anger. It is important that the father recognises the anger for what it is and tells those close to him when his behaviour is merely an expression of anger.

It is important that the father express his anger along with other emotional responses in order for it finally to be put to rest. It is likely that unexpressed anger may lead to unresolved anger, which in turn may lead to bitterness and sometimes depression. Bitterness (and resentment) occurs when person's entire view of life is tainted and distorted. In this case, the father refuses to see the beauty and goodness and joy which, in spite of the 'tragedy' of a diagnosis, still constitutes much of life with one's child. Ultimately the goal of grief is to say goodbye to previous dreams, hopes and aspirations that the father had for his child, to embrace the contribution that the child will make to his life, and to express gratitude for the child that he now has. To identify and express anger as a natural, human response is one of the steps on the way to acceptance of the diagnosis, and of the child.

- **Letting go of feelings:** Orphan (2004: 106) cautions against switching off or bottling up feelings as this expends too much energy which could be put to good use in order to deal with life and the situation in a constructive way. Tears are not only therapeutic but also release pent up emotions and the father may find much emotional release in crying together with his spouse. Unexpressed feelings will manifest in physical symptoms such as being run down, anxious and stressed, blood pressure conditions, illness, sleep disturbances and so forth (Orphan, 2004: 107). Working through the process of grief is something the father can only do for himself and the mother, family, friends and community needs to allow him the space to do so. Should the father find it difficult to deal with his feelings of grief, it is recommended that he solicit the services of a trained counsellor to gently facilitate this process. Once the father has reached acceptance, counselling may further direct him to reframe the life event on a cognitive level in order for him to have hope, and to develop strategies to turn this into a positive experience. This is imperative for the father to reach an acceptable level of quality of life for himself, for his child with DS, as well as for the rest of the family. The father who gets stuck in

the grief process may find himself in a deep depression from which he would seemingly be unable to find a way out.

- **Manage the anxiety:** It does not take long for most fathers to become aware that they, not some professional, are their child's medical, educational, and therapy managers, even though they may have minimal knowledge of these areas. That alone should drive home the urgent need for energies to be mobilized and focused by the crucial feeling of anxiety. Fathers should avoid relying on alcohol or medication as a 'solution' to the 'problem'. These solutions will keep the father from changing and may just make matters worse for all concerned. Realities must be faced, stressful as they might be.

The following are a few the **techniques** that can help a father deal with anxiety.

Progressive relaxation involves tensing and relaxing muscle groups in order from the tips of the toes to the top of the head. This causes breathing to become slower and deeper and for the father to relax. After about ten such tensing/relaxing sessions, the father can try to relax the muscles only without tensing while breathing slowly and deeply.

Deep breathing is a valuable exercise to replenish oxygen and help the body produce energy. This technique involves lying down and breathing slowly and deeply while feeling the expansion of the abdominal area before the ribcage expands. Doing this exercise for ten to fifteen minutes per day will improve breathing also during normal activities.

Mental vacationing is important to make the father feel good. Thinking about upsetting things tenses up the body as a result of the lower centres of the brain (which regulates body functions) which cannot distinguish between real images and those which are imagined. Hence, thinking anxious thoughts tenses the body. Preparing for a mental vacation involves that the father relaxes his muscles and takes a few deep breaths. He then closes his eyes and imagines he is someplace he enjoys. The father should fully engage in this imagined event (see the sights, hear the sounds, feel the air, smell the smells, and tune in to the sense of well-being) for approximately ten to fifteen minutes at a time. As he becomes more adept, he may find that he is able to feel like he has been on a long vacation or just returned from a good time in just a few minutes.

- **Face the fear:** As anxiety mobilizes the father to deal with change, fear is a warning that alarms him to the seriousness of the internal changes that are demanded. Fear concerning this life event dramatically challenges the father's sense of balance and order and he experiences the terror of knowing that he will be required to change on a fundamental level, against his will, with full understanding that the process of internal change is very difficult. Fear produces a sense of abandonment and vulnerability. We have numerous sayings to cope with this level of fear, such as "It is far better to have loved and lost, than to have never loved at all." Each

father should find his own words to confront the sense of abandonment and vulnerability generated by the significant loss he experiences regarding this life event. Fathers must caution against "over-protectionism," the gut-wrenching fear of permitting their differently abled child to do anything that feels risky. Fear is the medium that encourages the struggle to reattach to the child and to accept him despite his/her diagnosis.

- **Accept feelings as natural:** The father should allow himself to feel what he is feeling. Denying the feelings is tantamount to denying that anything has happened or changed. The father needs to experience and express the feelings of grief on route to acceptance. Feeling the emotions and feelings of grief may help the father to grow and benefit from what he might privately perceive as the worst tragedy of his life. Whatever platform the father chooses, his grief must be shared deeply and fully, until the underlying issues are revealed.

In dealing with his grief, the father may find that subconscious issues resurface. This should not alarm him. Issues that are reopened can change his world view and new perceptions of himself and his world and may serve as a solid foundation for coping with diagnosis of his child, as well as for personal growth. The father may find his inner strength. Dealing with grief may mobilize and focus the energies needed to change his life in order to attach to new dreams despite his feelings of vulnerability.

Hence, *experiencing* and *sharing* the pain is the *solution*, *not* the problem. When a father deals with the loss of the child that he had expected and the thought of a lifelong label on the child that he has now, he may be tempted to divert to his usual default reactive mode: This may include stifling feelings, overzealous devotion to work or profession, toughing-it-out, and innumerable other ways which keep him from experiencing what is happening to him. As such, he becomes one of the "walking wounded". It is, therefore, recommended that he should rather yield to the natural and necessary process of grieving, and also take advice from others who have been in similar situations, in order for him to formulate new definitions of what it takes to be a competent, capable, valuable and strong father, even though his child has a condition that he cannot cure.

Orphan (2004: 107) suggests that feelings are reminders of the difficult events that we have been through. As such, it is important to respect one's feelings as important, significant and valuable. A father who demonstrates to his family that feelings are natural and that he is able to manage his emotions, teaches his children a valuable lesson about emotional intelligence. As with everything else about DS, the siblings will take their cue from both mother and father. In turn, the parents can take a leaf out of the book of the child by showing others how they feel by using words, sound or behaviour and also by their easy-forgiving and non-judgmental natures. The lesson is that holding back the feelings may merely prolong the process of coming to terms with the situation.

Cognitive subsystem:

- **Realistic expectations:** The father should guard against having unrealistic expectations of himself and of his child with DS. Unrealistic expectations make you lose perspective. The father must realize that he does not have to be 'super-dad'; he just has to be a dad doing his best in his given situation. This requires a conscious mind-shift, which, unaddressed, can cause great anxiety for the father as well as the other family members. For most fathers this will be their first experience with disability, so not only does he have to rethink his own expectations of himself, but also those of the child with DS, of the other family members and society.
- **Rethink disability:** As a part of his new reality, the father may need to change his thoughts around disability. This knowledge needs to be internalized on a cognitive level first and foremost. The father's positivity may increase if he adopts a view of seeing his child for what he/she *can* do, rather than what they *can't* do, in other words focusing on the *ability*, rather than the *disability*. It may be beneficial to meet with other parents who have had positive experiences in raising their child with DS in order to reach a healthier understanding of the child as a unique individual. The father needs to understand the child's strengths (and challenges) and try to visualize what the experience of disability is actually like for his child with DS in order to empower himself to see this child in a different way.
- **Knowledge empowers:** As a father you will always be your child's number one advocate. It is therefore important to gain knowledge about the child's diagnosis and how the syndrome will affect him/her. The more information the father has, the better he is able to advocate for his child (and others with DS) and to educate people who are ignorant about DS. Being emotionally strong and having a sound knowledge base on the topic will permit the father to take a confident advocating stand in the community. This will support a trust relationship between the child with DS and his/her father and sustain resilience of the family unit.

Other valuable information may be to have a basic understanding of the developmental stages of a child in order to pitch expectations appropriately. Fathers often rely on the mother to find and share information on DS. However, building his own knowledge about DS and parenting issues will not only expand his knowledge, but also build his confidence as a result from an increased understanding of DS.

Physical subsystem:

- **Priorities:** The father needs to recognize and acknowledge what his priorities are.
- **Look after yourself:** You cannot give your child the care *they* need unless you know what *you* need. Looking after yourself is a state of mind. It is important that the father acknowledges that he is important, he is valuable and he deserves some time off just like any

other father. It is all about giving himself credit for coping in tough times rather than blaming himself and feeling guilty for not coping. The father needs to *take time for himself* when he can. For example, if he has gone through a particularly difficult time, rather than paint the garage or fix the shelf, take 'me time'. Be creative in the pursuit of spending time with your wife by considering a breakfast 'date' rather than an evening date that is inevitably postponed because of exhaustion or other logistic challenges.

- **Ask for help:** Raising a differently abled child is not a one- or two-person job, so work on a network of support. If someone you trust offers to have your child for a while, take them up on it. If it is your turn to babysit, call a friend who has a child and arrange an outing together. A simple ball-and-blanket outing to a park can feel like a long-weekend! Enlist the help of a volunteer to help with 'entertainment duty'. Students who study education, physiotherapy, speech therapy or early intervention are usually interested to help.
- **Practice mindfulness:** How a father reacts to stress will depend on his personality, emotional make-up and previous life experiences. It is important that he recognize his experience of this life event has in a sense made him more vulnerable and fragile. Father, be careful not to be so hard on yourself. Being able to admit to yourself how hard things are is a way of starting to deal with pent-up feelings that may cause blockages for clear thinking about day-to-day situations. Not dealing with stored up feelings may lead to depression and aggression that is damaging to relationships and family life in general. Become visible to those around you by letting people around you know how tough this road can be. Do this in a way that empowers yourself so that others do not load more pressure on you. You need to make sense of things. This means that you need to know as much as possible about DS. Empower yourself by gaining as much knowledge as you can.
- **Let go of expectations and pressures of performance-led parenting:** A vital part of parenting a child with DS is about developing safe spaces based on acceptance and love where the child can be allowed to be the unique individual that he was born to be. In such as space the child will develop in his own way. And both father and child can be who they are.

It is so much less stressful that way! Examples of such safe spaces may be a one-on-one puzzle building activity or a game where the child is allowed to express his/her emotions; it may also be a situation which the father creates an opportunity to develop the strengths of his child such as assisting the child on a jungle-gym, teaching him how to swing higher, or teaching the child how to ride a bicycle. Any indoor activity that includes the child in a one-on-one situation which teaches him new skills in a gentle nurturing environment will show the child that his/her father is guiding them to do and be *their* best.

- **The way it is:** Just talking about stress will not take it away. Life goes on and the father still has to live his life. This is the shared reality for all fathers of a child with DS. It serves the father to remember that he is not on his own and connecting to another father of child with DS may be a good place to start connecting to this reality.

Behavioural subsystem:

- **Avoid people who give unsolicited advice:** The father's emotional stability may be supported by time spent with someone who is caring and sensitive and will allow him to vent, or just verbalize his concerns and state of mind. The father does not necessarily need advice and should avoid people who tend to problem solve as a default. Thus, the father should best avoid persons who start their sentences with "God only gives *these* children to...", "If I were you..." or "It's not so bad... I hear that those kids..." Rather, he should confide in a friend or a father who has a child with DS who understands.
- **Relationships with professionals:** It is important that the father develops relationships with all professionals involved in his child's life. This includes people outside the medical team, such as therapists and school staff. By asking questions the father not only becomes fully informed about what supports the child is able to access, but it also shows the child's support team that the father is involved and pro-active. Although the internet is a good start to access information, it may be helpful for the father to make contact with other parents who are in a similar situation (especially parents of older children may have more exposure and experience) in order to compile a data base of reliable therapists, activities and services that the child may benefit from.
- **Attitude adjustment:** Do not dwell on what cannot be controlled or changed, as it serves no one and may result in relationship problems. Acceptance of the child, the diagnosis and the challenge requires an attitude adjustment toward himself, his child with DS and his child's future.
- **Flexibility:** In terms of overprotection of the child, the father (and mother) needs to create an environment of openness and trust, in which issues can be discussed and informed choices made. It would serve both the parents and the child with DS if the parents spoke with 'one voice' in order to avoid ambiguity. However, the father needs to revisit his parenting style and incorporate flexibility where necessary. Allow the child with DS to take decisions and make choices (these are already limited), as this will provide latitude for both father and child.
- **Avoid over compensatory behaviour:** Related to such behaviour, the father should avoid the following scenarios: a previously active sportsman suddenly staying at home to support his wife who is a stay-at-home mom and chooses not to make time for a hobby or participation in sport. Such an outward display of support may cause resentment toward the wife (and

possibly the child with DS that he may see as the 'cause'). On the other hand the father may immerse himself in work as an escape from his overwhelming new reality which he has come to perceive as a burden. The father should endeavour to maintain balance in his work and leisure activities as well as time spent by himself, with his spouse, as well as activities which involve the entire family unit.

Spiritual subsystem:

Fathers who follow the Christian faith may relate to this section.

- **Be a courageous parent:** It takes courage for the father to stand by his spiritual convictions in times of strife and turmoil. Hence, the father should not only be an ambassador for his child, but also show the child that he is always in his corner. An example may be of children on a playground and other children not taking turns. The father should in a gentle way explain to the group about taking turns fairly and including the child with DS in the game. Similarly, the father should be able to speak up if someone is passing unkind remarks about the differently abled or telling derogatory jokes. He should have the courage to stand up for his child's rights even if the child is not present in a situation.
- **Delight in your child:** An analogy used in *The Message* (a more contemporary version of the Bible), refers to a father who *delights* in his son. Strikingly descriptive, this terminology expresses the ideal feeling of every father for his child, and in turn, how every child would like his father to feel about him. The word *delight* embodies the expectation of the father-child relationship to include enjoyment, satisfaction, contentment and enchantment.

Men often struggle to say the words "I love you" to those they cherish most, and this burden, common to men, is passed from generation to generation. It may be time that fathers forgive their own father for giving them this burden. In order to move forward, it may be significant for a father to find the inner strength to tell his child with DS often how much he/she is loved.

A father, who not only follows the biblical principles, but also that of ordered civil society, provides the security to the mother and his children that he is absolutely committed to them. It is suggested that fathers not only teach the child physical, academic and emotional skills, but to instil spiritual and moral values as well. The child, who sees his/her father living a life that is exemplary, will want to follow that model.

Fathers who follow the Christian faith may also know that the Gospel of Matthew, 3: 16-17 says: "As soon as Jesus was baptized, he went up out of the water. At that moment Heaven was opened, and he saw the Spirit of God descending like a dove and lighting upon him. And a voice from Heaven said, '*This is my Son, whom I love; with him I am well pleased.*'" At closer inspection we see what God, the Father did for his son Jesus. First, he claimed Jesus as his own, saying, "*This is my son.*" Next, God the Father said the words every child needs to hear

directly from his own father's lips: "*I love you.*" And finally, God the Father affirmed his son Jesus, saying, "*I am well pleased*". So by following the best example of loving your child, parents should do as God (our Father), not recommended, but commanded: Love your child!

Fatherly pride enables him to proclaim: "That's my boy! /that's my girl!" when a child accomplishes something. He may say it out loud in the presence of strangers or friends, yet often he forgets to say these words to the very person who needs to hear it most and most often. God sets the example and in His departing command, He urges us to remember what He had done, remember the example He had set and to do the same. Telling your child that you love him is not a choice. It is an order from the High Commander Himself.

- **Be proud of the person your child is, and you will be proud of the person he will become:** God the Father publicly declared his pleasure in Jesus as a person even before he began his public ministry. This was not based on his performance. God's love for his son was unconditional. Fathers are urged not to wait for their child with DS (or any of his children) to bring home report cards, merit certificates, team jerseys or even a clean room, but to tell them every day that they are pleased with them just because they are who they are. The example is set, when, in the final act of his blessing, God the Father affirms Jesus, stating, "With him I am well pleased".

THEME TWO: INTER-PERSONAL EXPERIENCES OF THE FATHER

Relationship to self

- **Realize that you do not need to justify your worth:** Because the nature of the role of the father is performance based, fathers often think "If I do A, then I am worthy of B". This thought is both destructive and wrong, as it presumes some hierarchy of people's worth exists. The truth is that everyone is worthy of love, respect and kindness. The father who internalizes that, and directs it to self, is able to direct it to others.
- **Let go of expectations:** This will probably be one of the most important things a father can do. It may be hard to let go of the idealized image of what his life were going to look like with his child (or his own life before the birth of the child with DS). However, once he is able to make such a cognitive shift, it is easier to accept things for what they are, without feeling that his whole world is crumbling before him.
- **Know that fitting in is overrated:** This life event forever places the family unit in a fishbowl, with society seemingly 'fascinated' by how 'normal' (or not!) the family unit functions with a child born with one extra chromosome. In a one-size-fits-all society, that which is different, stands out, and is not always understood. Having a few close friends is sufficient. True friends will not leave on a whim. They will appreciate him for his amazing qualities rather than his

'role' or 'compatibility' to fitting any fixed mould. A father who is himself will attract authentic friendships into his life. A practical recommendation would be to include his child in certain group leisure activities where fathers would normally take their children so that society may gain exposure to the child with DS and vice versa. Such activities may include taking his child with to a sports match, a fishing trip, an informal golf day, a cycle event and so forth. Should the father's type of work permits, taking the child to work on a Saturday morning and for a breakfast thereafter may also strengthen the father-child bond.

- **Nothing is set in stone:** It serves no one to berate oneself for what has happened. Realize that life is full of opportunities. Any time spent on 'what could/should have been' allows less time to enjoy the opportunities that are presenting themselves – even under unexpected circumstances! Moping about what could have been will serve neither the father, nor the child with DS and the father may never come to realize the wonderful aspects about his child. Rather focus on what is positive about the situation and the abilities of the child. Many children with DS also have other multiple health challenges. A father of a child who has a single diagnosis, for example only DS, has much to be grateful for. There are always ways to identify and celebrate the positive in any situation and the father should make a concerted effort to focus on that which is practical, positive and realistically achievable when it comes to his child.

Spousal relationship:

- **Put the relationship first:** The couple must refocus their attention to their commitment to each other. This entails spending quality time together. The father must remain vigilant of his own behaviour toward his wife, bearing in mind that she may feel frustrated for not being able to have the option of spending much time apart from looking after the child with DS and tending to his/her needs. The father should make a concerted effort to be kind and acknowledge the stress that they are both under, to avoid hurtful criticism, and to avoid negativity.
- **Discuss feelings:** Meaningful communication is the way to explore a deeper understanding and a connection. This is established by communicating one's needs, concerns, feelings and anxieties. Talking through issues lead to joint, sound decisions. No matter how hard, the father should communicate his personal fears and anxieties to his partner, and allow her the space in which to do so. Sharing the feelings of grief shares the burden. It is important to remember that time *does* lessen the pain, even if it does not heal all wounds. The excruciating fear, rooted in the uncertainty surrounding the future of their child, can be devastating to new parents. Unless they are able to discover a common space of acceptance and understanding, their relationship and marriage may suffer irreparably.
- **Schedule dating:** Spousal support also entails that the father and mother spend social time together away from the home and children. Scheduling occasional 'dates' which focus on

anything but the children, treatments or the diagnosis, and includes fun and laughter, are a must.

- **Share hands-on parenting:** The father's hands-on active participation in parenting his child with DS will be the best display of spousal support. As one father commented, "*It's not an easy road for any parent. Along the way we have to lift the other partner up to be the best parent(s) we can possibly be for our children. We have to constantly mentally motivate each other as a parent*".

Father's relationship to siblings:

- **Communication:** By implication effective family communication eases problem solving, maintains healthy relationships, and lowers stress. The father should therefore create an emotionally safe place at home that will encourage his child with DS and siblings to share anxieties and concerns, hurts and disappointments. This is facilitated by positive speaking, which means being encouraging and kind to the other person, addressing them in a respectful manner that says 'I care about you and I care about your feelings'. It also involves openly and honestly sharing own feelings, experiences and thoughts which, in turn, invites their input.
- **Appreciation for every child:** Appreciation is shown in multiple ways: spending individual meaningful time together (even if it is for short periods); pointing out the good qualities in others; hugs and other encouraging touch and goodwill gestures; congratulating the individual child on accomplishments big and seemingly insignificant; speaking about all his children in a positive way.
- **Prepare but do not scare:** Sibling preparation should be a priority. Both parents (not just the mother), should explain to the sibling with the greatest diplomacy and circumspection, on their level of understanding, the implications of having a differently abled sibling. Provide simplistic answers to questions and caution against overload. Such a session should be informal yet planned without interruption of phone calls or television. It is important to remain pro-active, positive and calm during this session. Not only does this inform siblings adequately, but remaining calm, positive and pro-active also serves to alleviate much of the internal stress of both parents at this time.

Typically developing siblings have different reactions to their sibling with DS at different ages. The following information may be valuable as a reference for fathers who may not always understand the questions or reactions of siblings. Gannon (2008) suggests the following guidelines in this regard:

Under age three: the sibling is unlikely to understand the concept of *different* but will be sensitive to the tension or stress in the family. One father confirmed, "*It created a lot of anxiety*

for my daughter, who was two and a half when he was born, as she could pick up something was wrong but she didn't know what."

From age four: the sibling may not understand why their sister or brother cannot do things that they can;

Age six or seven: the sibling wonders about the permanence of the disability and view it as an illness from which there is potential recovery;

From age eight the sibling may begin to compare their own situations with friends, with increased awareness of their own situation. However, as the majority of children believe that their family situation is normal, they might not be able to compare their situation to a family without a differently abled child.

Father's relationship to friends and family:

- **Ask for help:** Asking for help is difficult for most fathers. This may be attributed to the culture of self-reliance in which we live. Do not feel guilt or shame for asking for help. Fathers often fear overburdening family and losing friendships by asking for support. However, to *not* ask for help and support *is* compromising these relationships. Reconsider your possible view of coping as just 'getting on with it'. Friends and family expect to help, but often do not know *how* they can help unless they are provided with clear guidance in this regard. Fathers should avoid constructed belief systems brought on by painful emotions that harbour thoughts such as: "This is my responsibility, I should be able to handle it", or "Others have enough problems of their own; they do not want to hear about mine." Despite probable physical exhaustion and emotional and cognitive fatigue, don't play down how hard things are or simply ignore them. For the sake of his emotional well-being, the father should rather ask for any physical help, accept an empathetic shoulder, or rely on a friend to be a sounding board.
- **Give back in return:** It makes sense for fathers, as human beings who are naturally sociable and gain emotional strength as well as practical support from others, to have more people involved in their lives. Even if this involvement is setting an example, giving advice, or just being present to a given situation; in turn, they also gain enormously from being in the lives of others. Such is the symbiosis of human existence. It stands to reason that a father who has a positive experience of support from another father of a child with DS (preferably older and wiser to the challenges and pitfalls), may feel compelled to reach out to other fathers in turn.

THEME FOUR: MANAGING THE LIFE EVENT

- **Take the role of spiritual teacher and mentor seriously:** Fathers of the Christian faith will base much of their fathering on their faith and belief system. A good father will not only promote the faith, but will also lead by example. Outside of his family unit, this example may include acts of benevolence to those less fortunate. A father who engages in spiritual guidance for his child provides an invaluable resource for leading with life's many challenges.

- **Show your love:** A highly effective father is not ashamed to say ‘I love you’ and does not hesitate to shower his child with physical expressions of love. Showing affection is a sign of love, not a sign of weakness.
- **Balance:** It is important that fathers of a child with DS remember that they have the same needs and rights as any other father: good health, emotional well-being and good family relationships. In line with other studies (Skotko et al, 2011: 2341). All fathers learn new skills and become adept at managing a range of challenges that circumstances necessitate with relation to a child with DS. The concept of *dis*-able or *dis*-ability are optional, however, *to make able* is what make resolutions, solutions and triumphs remarkable, in any family, but more so in families with a differently abled child. Parents of children who are differently abled do not become super parents, but they do become parents with uncommon skills. The challenges they face are physical, emotional, financial, logistical, intellectual, and above all, constant.

Not every father is equally adept at keeping these “juggling balls” in the air at the same time, which is hardly surprising, given that *this* is a balancing act of the highest order. Allowing the family to be what it *is*, rather than clinging to a preconceived perception is of what it *should* be, go a long way toward establishing constructive adjustment as a base for firmer footing and an imminent juggling success.

- **Coping with stress:** Potter (2014: 472-488) recommend the following strategies to cope with stress. These strategies refer to the alternative method to coping with stress, in which one works to minimize their anxiety and stress in a preventative manner. If the father works towards coping with stress daily, the feeling of stress and the ways in which he deals with it as the external event arises becomes less of a burden.

Suggested strategies to improve stress management include:

- Regular exercise – set up a fitness program, 3–4 times a week
 - Support systems – to listen, offer advice, and support each other
 - Time management – develop an organizational system
 - Guided imagery and visualization – create a relaxing state of mind
 - Progressive muscle relaxation – loosen tense muscle groups
 - Assertiveness training – work on effective communication
 - Journal writing – express true emotion, self-reflection
 - Stress management in the workplace – organize a new system, switch tasks to reduce own stress.
- **Highly adaptive/active/problem-focused mechanisms:** These skills refer to strategies which can be used to deal with negative emotions experienced by stress in a constructive manner. In a manner of speaking, these skills can be referred to as ‘facing a problem head on’ (Lefcourt, 2001: 70).

Affiliation involves dealing with stress by turning to a social network for support, but the father does not share with others in order to diffuse or avoid the responsibility (Lefcourt, 2001: 71). **Therapeutic humour** refers to any intervention that promotes health and wellness by stimulating a playful discovery, expression or appreciation of the absurdity of or incongruity of life's situations. When one laughs during a tough situation they feel absent from their worries, and this allows them to think differently (Lefcourt, 2001: 73).

This intervention may enhance health or be used as a complementary treatment of illness to facilitate healing or coping whether physical, emotional, cognitive, or spiritual (Lefcourt, 2001: 72). Sigmund Freud suggested that humour was an excellent defensive strategy in emotional situations (Lefcourt, 2001: 72). (2001: 75) suggests that this perspective-taking humour is the most effective due to its ability to distance oneself from the situation of great stress. **Sublimation** allows an "indirect resolution of conflict with neither adverse consequences nor consequences marked by loss of pleasure. Essentially, this mechanism allows channelling of troubling emotions or impulses into an outlet that is socially acceptable (Valiant, 2000). **Positive reappraisal** redirects thoughts (cognitive energy) to good things that are either occurring or have not occurred. This can lead to personal growth, self-reflection, and awareness of the power/benefits of one's efforts (Folkman & Moskowitz, 2000). Other adaptive coping mechanisms include anticipation, altruism, and self-observation.

- **Rethink your parenting style:** Parenting styles and parenting skills require constant self-reflection, especially for the father of a child with DS. As described by Pretorius (2005: 62), a warm parenting attitude from the father has a positive effect on a child and the child-father relationship. Warm parenting supports the most important aspect of child rearing: the lovingness of the "I - you" relationship between parent and child. Warm parenting encourages nurturing, supportive and affectionate conduct toward the child. Especially in the case of a child with DS, encouragement, praise, showing interest and offering the child loving care and protection indicates the parents' acceptance of the child. As with any other child, the father should also include the child with DS in discussing plans, setting realistic goals and offering wise advice to further support a strong relationship between parent and child.
- **Embracing positive family dynamics:** As expressed by Pelchat et al (2003: 241) it is appropriate for parents to share the power in a family and support each other in decision-making surrounding their children, avoiding damaging alignments and hierarchies that may hamper optimal family functioning. According to Pretorius (2005: 44-45), positive family dynamics is also encouraged by identifying the strengths of each individual within the family and acknowledging the value of their attributes. An authoritative parenting style, which values and respects the opinion of each individual, will yield positive outcomes for the family with a differently abled member; whilst firm boundaries with appropriate discipline, strong, sound

family values, attainable, realistic goals and positive, warm and supportive interaction between family members encourage sound family dynamics.

- **Rethink family functioning:** Family functioning is a multi-dimensional concept. In the researcher's experience effective family functioning relies on nurturance and support which includes the provision of comfort, warmth and reassurance as a reciprocal role between family members. Both parents could provide this affective role, for example either parent can comfort a child who has had a bad day at school, or family members can support one another after the death of a loved one, or in this case, upon being given an unexpected diagnosis of their child. Family functioning also leans heavily on life skills development and this role includes the physical, emotional, educational and social development of both the children and the adults in a family. Again the father's prominent role is evident in this in this facet of family functioning.
- **Vulnerability and mindfulness:** The general view of society that disability is a tragedy, reinforces the unspeakable sadness that a father feels when he receives the diagnosis that the perfect child that he had *expected* is *not* perfectly perfect (Woolfson, 2004: 9). Most fathers experience feelings of sadness and helplessness, yet this situation remains complicated to define, because the child is still present, as opposed to a situation where a child has passed away.

Some fathers perceive the diagnosis as a tragedy, not only for themselves, but also for the child, and thus they take 'ownership' of their 'tragedy'. It may happen that the family ('they' become the tragedy). In reality, if the father is able to separate the *child* from the *diagnosis*, thus seeing this life event as '*the story*' and not '*their story*', he reinforces his own capacity for acceptance of his child by leading his family by example to see his child as separate from the syndrome. That is, seeing the child as a *human being and a child first*, and the *diagnosis* secondary to all that.

- **Show grace to self:** The researcher recalls a Buddhist saying: "I see you Mara. Let's have tea". The simplicity of this quote holds much truth for the father who yearns for things to be as they were before. Yet he finds himself inside this 'tragedy', with his limited understanding of *why* this is happening to *them*, *how* this space is making him *feel*, and *how* he can return to the 'illusion' of 'normality' which was his family's perfect-picket-fence (complete with landscaped garden), prior the diagnosis. Noting the thought, *Mara* personifies the illusion or the shadow; that which needs to be *seen*, that which the father needs to *be* with, in order to transcend his current state of mind; the state of compulsion to run away from it all.

Most fathers can relate to such an intricate reference to the 'deficiency'/'disability'/'dysfunction' as well as the experiences and emotions that are aroused from and through the diagnosis. In order for the father to see it and to *observe* it, it needs to be *allowed* – the 'pretty' *and* the 'not-so-pretty' – with non-judgement and compassion. The father needs to *be* with this, and be

alright with it as it presents, without the need to change anything in any given moment. The researcher, having first-hand insight of this space, understands what this father experiences at this time. Not being embarrassed to share his intimate perception of the experience, and acknowledging thus, aids the journey toward acceptance. Evident from his response, this father's personal growth was facilitated by him giving *himself* permission to *allow* the pretty and the not-so-pretty of this challenge to be acknowledged, to then, without judgement, let it go with compassion for himself, his child and the other role players in this 'tragedy'.

According to Neuropsychologist Rick Hanson (2013) the shift in paradigm then moves from 'I did not sign up for this' (the tragedy), to 'I signed up for this'. The father accepting that *it is as it is*. Thus, acknowledging that *this* situation is out of his control. Hanson further suggests that fathers should avoid blaming anyone for what had happened, they should not discount their own weariness and stress, but rather establish themselves in a *relationship of choice* toward *that* which is challenging. Hanson says "Honour yourself for the hard things you're dealing with." A gentle reminder for fathers of children with DS to show grace to *self*.

- **Perfection is in the eye of the beholder:** Fathers with sons often equate their expectations of their sons to the expectations of self. In this case, this father sees himself as a part of an 'imperfect' family, since the diagnosis of his child. But because "perfect" is an impression, the father finds himself projecting the duality of reality. In a manner of speaking, 'seesawing' between the illusionary states of what constitutes a perfect or an imperfect family. Which brings rise to the questions: What is perfect? What is imperfect? This father clearly grapples with this concept. However, he recognizes this internal battle and acknowledges that 'it is getting better'. Such presence in the moment is true mindfulness. Not needing to 'fix' or 'change' anything in the moment, but simply acknowledging the magnificence of another human being: his child (extra chromosome and all!)

Support for the father:

- **Support groups:** At times when fathers may feel isolated, such a space may provide perspective: knowing that 'I am not the only one in this situation'. Within a support group (space of solidarity), fathers can let off steam without anyone thinking any worse of them. Older parents will provide positive but realistic ideas about the future. Most importantly, it provides a space where fathers can laugh about everyday situations without giving or taking offence.
- Addendum C offers guidelines for establishing a chapter for fathers.

PRACTICAL RECOMMENDATIONS TO THE MEDICAL FRATERNITY

- Relay a diagnosis with **compassion** and an appropriate degree of hope for the child and parents within an atmosphere of nurturing and partnering. However, avoid sympathy, as this

forces the parents into emotional, physical, behavioural and spiritual 'mourning' immediately. If offered sympathy, the parents think they have heard a death sentence. It is therefore recommended that health workers and especially the doctor steer clear of using impersonal pessimistic terminology in a morbid tone of voice. Findings from this research confirm that the manner in which a diagnosis is explained to parents can have a profound and prolonged effect on the parent's attitudes toward their child and professionals. Especially when the doctor lapses into medical jargon to mask his own discomfort with the situation. It is imperative that the medical staff, especially the doctor, congratulate the parents on the birth of the child, as they would in any other case, and then provide as much emotional and physical support as possible in terms of the practicality of this unexpected event for the parents.

- **Meet the parents prepared:** Be prepared for the many answers that parents will want at this time. The paediatrician, gynaecologist and senior maternity and paediatric nursing staff need to be knowledgeable on DS. Have a database of parents, or consultants, who have been through this in order to recommend the parents to someone who has first-hand knowledge. The senior nurse should inform the parents in a gentle way that such a visit can be arranged, without forcing the parents into a space that they are not yet ready to explore. The researcher has on several occasions met the parents (and families) after the birth of their baby. It is both rewarding and enlightening to be the first voice of reason in the emotional tsunami of such a family, and to witness how the burden literally lifts as new parents become empowered by positive input, enabling them to see their baby as a treasured human being first, and not as a diagnosis or genetic statistic.
- **Caring treatment by hospital staff:** It is recommended that all staff in the maternity section of every hospital receive some training to equip them to deal with the mother in a sensitive, caring, respectful and knowledgeable way. In reality this does not happen often and the patronizing and inappropriate statements which are often made clearly reflect a combination of lack of compassion and ignorance. It is essential that paediatricians, gynaecologists and maternity and paediatric staff familiarize themselves with DS and keep up to date with current information, focusing on the positives (most of the books and internet sites offer the negatives anyway) in order to furnish parents with answers and advice which they inevitably seek immediately after diagnosis. Most importantly, provide positive input by focusing on what the child will be *able* to do vs. what he/she will be *unable* to do. An affirmative attitude from health workers may be pivotal in the positive paradigm shift of parents.
- **Include the father:** Although the mother often leads the questions and therefore becomes the focus for responses, the role of the father must not be underestimated, remembering, too, that his shock and feelings of anxiety may be even more heightened at this stage. The father must therefore be treated with equal importance at meetings.

- **Make a courtesy call:** Although doctors rarely phone parents afterwards, a courtesy call under these extraordinary circumstances will be extremely valuable to the parents as a comfort that they are not alone and that their doctor cares about their well-being and that of their child.
- **Practical suggestions:** Nursing staff should caution against doing everything for the baby in order to let the mother rest. Physical contact will encourage bonding and should be recommended. Remark about how beautiful and healthy the baby is. Be helpful and positive about breastfeeding (often babies with DS have a problem with breastfeeding due to low muscle-tone, or they are very lethargic, which could indicate a heart problem). Ask parents how much and what types of **communication** they find helpful and build rapport with honesty and caring. Encourage parents to ask questions and express their emotions.

Try to determine each time you communicate with the parents their level of **adjustment** and assess what they have been able to internalize and understand regarding what you have discussed. Reinforce the practice of parent participation in helping their child learn and develop. Understand and accept parental ascendance through the stages of adjustment as being a normal process and support them. Adjustment can speed the process of achieving acceptance.

PRACTICAL RECOMMENDATIONS TO THE COMMUNITY

- **A change of attitude required:** The general society commonly displays an apathetic attitude toward the differently abled. It is often not the syndrome itself, but the way it is interpreted that impacts on the individuals with DS and their families. The father does not need sanctification; he is just an ordinary person with extraordinary circumstances. What he needs is acceptance of his child as a human being capable of contributing positively to society if given the chance. As mentioned before, members of the community will take their cue from the father. It is, therefore, imperative that the father treat his child with dignity and respect especially when they are in public.
- **Take your cue from the father:** The father plays an important part in creating a positive awareness within the extended family circle by his active involvement in parenting the child with DS. The father sets the tone by example by the manner in which he treats his child in public, speaks *to* and *about* his child, the measure of patience he affords the child, and his tolerance toward the challenges of his child. This is the cue for society to do the same.
- **Follow the leader:** If the father has taught his child simple, practical tasks towards independence and by guiding the child toward autonomous decision taking, the father has encouraged *ability*, rather than support *disability*. Society should again follow the leader in this case. Allocating routine menial tasks will teach the child a sense of accountability and build his

self-esteem. If the mother and father makes an active effort to get together with others socially and engage in community projects which involve the child with DS, members of society should embrace the opportunity to play an active part in inclusion of this child into society. Increased inclusion into society has a positive spin-off: for the child it instils a sense of belonging and participation in regular activities, and for society a broader acknowledgement of how *able* a differently abled individual can be. Thus, every opportunity should be embraced by society to get more people to see beyond the disabilities of persons living with DS and to celebrate their accomplishments.

LIST OF FIGURES AND TABLES

FIGURE 1.1:	24
Researcher's adaptation of the systemic model of individual functioning	
FIGURE 1.2:	35
Data analysis in qualitative research	
FIGURE 2.1:	56
Defence mechanisms deployed by 'ego' state	
FIGURE 2.2:	56
Fixation, cause and effect on adult personality	
TABLE 1.1:	26
Differences between quantitative and qualitative approaches	
TABLE 1.2:	27
Characteristics of the quantitative and qualitative approaches	
TABLE 1.3:	36
The core differences between quantitative and qualitative analysis	
TABLE 5.1:	162
Summary of themes, sub-themes and critical aspects	