Exploring the support needs of parents of infants with complex health needs in the community

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Declaration of candidate

I hereby solemnly declare that this dissertation, *Exploring the support needs of parents of infants with complex health needs in the community*, presents the work carried out by myself and to the best of my knowledge does not contain any materials written by another person except where due reference is made. I declare that all the sources used or quoted in this study are acknowledged in the bibliography; that the study has been approved by the Ethics Committee of the North-West University and the head of departments involved in the study; and that I complied with the ethical standards set by the North-West University.

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ABSTRACT

The survival rate and life expectancy of infants with complex health needs have increased over the last decades, and this increases the number of families who have to care for such infants at home. These families seek support in the community setting, and supporting them has a positive impact on the well-being of both the parents and the infant.

In South Africa the needs of these parents are not known, and this fact makes it difficult to adequately support them in the community. The aim of this study was to explore and describe the needs of parents of infants with complex health needs in the community setting.

Two objectives were set to reach the aim mentioned above: 1) to critically appraise and synthesise the best available evidence on the support needs of parents of infants with complex health needs and 2) to explore and describe parents' emic perspective on their support needs as parents of infants with complex health needs in a South African context.

A sequential mixed method approach was utilised in two phases, here discussed in five chapters. In an attempt to meet objective one, the support needs of parents of infants with complex health needs were determined by means of an integrative literature review from studies obtained through computerised searches of several electronic databases, supplemented by checking reference lists and consultation with experts. This was followed by individual face-to-face interviews with the stated parents in three different settings. The latter addressed the second objective of the study, namely to provide an emic perspective on the support needs of parents of infants with complex health needs in a South African context.

The integrative literature review described five main themes on the support needs of parents of infants with complex health needs: need for information, need for parent-to-parent support, need for professional support, need for self-confidence in the care of the infant and need for social support. All of these themes were confirmed in the South African context through the interviews with parents. However, South African parents added an additional theme: the need for normality.

The final chapter offers an evaluation of the study and discusses study limitations and recommendations for nursing practice, education and research.

Key words: parents, support needs, infant, complex health needs, special needs, community, integrative literature review, mixed method approach.

OPSOMMING

Die oorlewing en lewensverwagting van babas met komplekse gesondheidsbehoeftes het verhoog oor die afgelope dekades en dus het die aantal gesinne wat vir hierdie babas by die huis sorg en hulp nodig het in die gemeenskap vermeerder. Ondersteuning van hierdie ouers het ‘n positiewe impak op die welstand van die ouers en die baba.

In Suid-Afrika is die behoeftes van dié ouers nie bekend nie, wat dit moeilik maak om hulle voldoende te ondersteun in die gemeenskap. Die doel van hierdie studie was om die ondersteuningsbehoeftes van ouers met babas met komplekse gesondheidsbehoeftes te beskryf en verken.

Die doelwit is bereik deur twee doelstellings aan te spreek: 1) om die beste navorsingsbewyse oor ouers met babas met komplekse gesondheidsbehoeftes se ondersteuningsbehoeftes krities te beoordeel en sintetiseer en 2) om hierdie ouers se behoeftes te verken en beskryf deur ‘n deelnemersperspektief oor hulle behoeftes in ‘n Suid-Afrikaanse konteks.

Die navorsing is in twee fases gedoen deur middel van ‘n benadering van sekwensiële gemengde metode en is in vyf hoofstukke bespreek. Die eerste doelstelling is beantwoord deur middel van ‘n geïntegreerde literatuuroorsig van studies wat verkry is deur gerekenariseerde soektogte van verskeie elektroniese databasisse, aangevul deur die nagaan van bronnelyste asook deur konsultasie met deskundiges. Die geïntegreerde literatuuroorsig is gevolg deur individuele onderhoude met ouers om die tweede doelstelling te beantwoord en dus ‘n deelnemersperspektief te verkry oor die ondersteuningsbehoeftes van ouers met babas met komplekse gesondheidsbehoeftes in ‘n Suid-Afrikaanse konteks.

Die geïntegreerde literatuuroorsig het vyf temas oor die ondersteuningsbehoeftes van ouers geïdentifiseer: die behoefe aan inligting, die behoefte aan ouer-tot-oueronderssteuning, die behoefte aan professionele ondersteuning, die behoefte aan selfvertroue in die versorging van hulle baba en die behoefte aan sosiale ondersteuning. Hierdie temas is ook bevestig deur die onderhoude in ‘n Suid-Arikaanse konteks, maar een addisionele tema is bygevoeg: die behoefte aan normaliteit.

Die finale hoofstuk van die navorsing behels die bespreking van die evaluasie van die studie, en beperkinge is geïdentifiseer en aanbevelings gemaak vir verpleegkunde praktyk, -onderwys en –navorsing.

Sleutelwoorde: ouers, ondersteuningsbehoeftes, baba, komplekse gesondheidsbehoeftes, spesiale behoeftes, gemeenskap, geïntegreerde literatuuroorsig, gemengde metode.

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TABLE OF CONTENTS

CHAPTER 1: OVERVIEW OF THE STUDY 1

1.1 INTRODUCTION TO THE CHAPTER 1

1.2 BACKGROUND TO THE STUDY 1

1.2.1 PARENTING CHALLENGES 1

1.2.2 AVAILABILITY AND QUALITY OF SERVICES 3

1.3 PROBLEM STATEMENT 5

1.4 RESEARCH QUESTION 5

1.5 AIM AND OBJECTIVES OF THE STUDY 5

1.6 SIGNIFICANCE OF THE STUDY 5

1.7 PHILOSOPHICAL FOUNDATION 6

1.7.1 CENTRAL THEORETICAL ARGUMENT 6

1.7.2 META-THEORETICAL PERSPECTIVE 6

1.7.3 THEORETICAL PERSPECTIVE 7

1.7.4 METHODOLOGICAL PERSPECTIVE 9

1.7.5 DEFINITION OF KEY CONCEPTS 10

1.7.5.1 Community 10

1.7.5.2 Complex health needs 10

1.7.5.3 Infant 10

1.7.5.4 Parental support needs 10

1.8 RESEARCH APPROACH 11

1.9 OUTLINE OF THE STUDY 11

1.10 CONCLUSION 12

CHAPTER 2: JUSTIFICATION OF RESEARCH APPROACH AND METHODS 13

2.1 INTRODUCTION TO THE CHAPTER 13

2.2 RESEARCH APPROACH 13

2.3 SETTING 15

2.4 RESEARCH METHODS AND PROCEDURES 16

2.4.1 INTEGRATIVE LITERATURE REVIEW AS METHOD OF CHOICE 16

2.4.2 THE INTEGRATIVE LITERATURE REVIEW PROCESS 17
2.4.2.1 Formulating the review question 18
2.4.2.2 Search strategy....19
2.4.2.3 Critical appraisal 21
2.4.2.4 Data analysis and synthesis....22
2.4.2.5 Concluding statements 23
2.4.2.6 Rigour of the integrative literature review 23
2.4.3 FIRST POINT OF INTERFACE 26
2.4.4 INTERVIEWS 26
2.4.4.1 Recruitment 26
2.4.4.2 The sample....27
2.4.4.3 The interview process 27
2.4.4.4 Field notes 28
2.4.4.5 Analysis of the data....29
2.4.4.6 Rigour of the interviews 29
2.5 ETHICAL CONSIDERATIONS....30
2.6 CONCLUSION....32
CHAPTER 3: REALISATION OF THE INTEGRATIVE LITERATURE REVIEW.... 33
3.1 INTRODUCTION TO THE CHAPTER....33
3.2 STEPS OF THE INTEGRATIVE LITERATURE REVIEW....33
3.2.1 THE REVIEW QUESTION 34
3.2.2 REALISATION OF THE SEARCH....34
3.2.2.1 Data source 1: Electronic databases via search platforms 34
3.2.2.2 Data source 2: Databases via the catalogue not included in the platforms of stage one....36
3.2.2.3 Data source 3: Journals via the alphabetical journal list not included in the first two stages 37
3.2.2.4 Data source 4: Pubmed and Google Scholar 37
3.2.2.5 Data source 5: Manual search of the reference lists of the articles included for critical appraisal 38

3.2.2.6 Data source 6: Personal contact with prominent published researchers in the field via e-mail 38
3.2.2.7 A summary of the realisation of the results of the search 39
3.2.3 CRITICAL APPRAISAL 42
3.2.3.1 Role of the independent reviewer 43
3.2.3.2 Appraisal results 43
3.2.4 DATA ANALYSIS AND SYNTHESIS WITH CONCLUDING STATEMENTS 45
3.2.4.1 Need for information 49
3.2.4.2 Need for parent-to-parent support 55
3.2.4.3 Need for professional support 58
3.2.4.4 Need for self-confidence in the care of the infant 65
3.2.4.5 Need for social support 67
3.2.5 CONCLUDING STATEMENTS 69
3.3 FIRST POINT OF INTERFACE 70
3.4 CONLCUSION 70
CHAPTER 4: REALISATION OF THE INTERVIEWS 71
4.1 INTRODUCTION TO THE CHAPTER 71
4.2 RECRUITMENT 72
4.3 THE SAMPLE 73
4.4 THE INTERVIEW PROCESS 73
4.4.1 ARRANGING THE INTERVIEWS 74
4.4.2 CONTRACTUAL RELATIONSHIP WITH PARTICIPANTS 74
4.4.3 THE INTERVIEWS 74
4.4.4 INTERVIEW GUIDE 75
4.4.5 TRANSCRIPTION OF THE INTERVIEWS 77
4.5 FIELD NOTES AND REFLECTION ON THE INTERVIEWS 77
4.6 ANALYSIS AND SYNTHESIS OF THE DATA (SECOND POINT OF INTERFACE) 78
4.7 FINDINGS 79

4.7.1 NEED FOR INFORMATION 81
4.7.2 NEED FOR PARENT-TO-PARENT SUPPORT 84
4.7.3 NEED FOR PROFESSIONAL SUPPORT 87
4.7.3.1 Need for counselling 87
4.7.3.2 Need for a service coordinator 88
4.7.3.3 Need for accessible and approachable professionals 89
4.7.3.4 Need for professional services 90
4.7.4 NEED FOR SELF-CONFIDENCE IN THE CARE OF THE INFANT 92
4.7.5 NEED FOR SOCIAL SUPPORT 95
4.7.6 NEED FOR NORMALITY 98
4.8 CONCLUSION 101
CHAPTER 5: EVALUATION, LIMITATIONS AND RECOMMENDATIONS OF THE STUDY 102
5.1 INTRODUCTION TO THE CHAPTER 102
5.2 EVALUATION OF THE STUDY 102
5.2.1 EVALUATION OF ACHIEVEMENTS OF THE OBJECTIVES 102
5.2.1.1 Objective 1: The integrative literature review 102
5.2.1.2 Objective 2: The interviews 103
5.2.2 EVALUATION OF RIGOUR 103
5.3 LIMITATIONS 105
5.3.1 LIMITATIONS OF THE STUDY 105
5.3.2 LIMITATIONS OF THE INTEGRATIVE LITERATURE REVIEW 105
5.3.3 LIMITATIONS OF THE INTERVIEWS 105
5.4 RECOMMENDATIONS 106
5.4.1 RECOMMENDATIONS FOR PRACTICE 106
5.4.2 RECOMMENDATIONS FOR EDUCATION 107
5.4.3 RECOMMENDATIONS FOR RESEARCH 107
5.5 CONCLUSION 108

LIST OF TABLES

Table 2-1: The steps of the integrative literature review 18
Table 2-2: Variables of the research question 19
Table 2-3: Summary of strategies used to enhance rigour of the integrative literature review 25
Table 3-1: Reasons for excluding full text articles read 40
Table 3-2: Critical appraisal results 44
Table 3-3: Need for information - outline of analysis 50
Table 3-4: Need for parent-to-parent support theme - outline of analysis 56
Table 3-5: Need for professional support - outline of analysis 59
Table 3-6: Need for self-confidence in the care of the infant - outline of analysis 66
Table 3-7: Need for social support - outline of analysis 68
Table 4-1: Interview guide 76
Table 4-2: Analytical framework utilized for analysis of interviews 78
Table 4-3: Summary of concluding statements supported by the interviews 99

LIST OF FIGURES

Figure 1-1: Sequential mixed method approach as illustrated by Creswell (2009) 11
Figure 2-1: First and second point of interface 15
Figure 3-1: Phase 1 - integrative literature review 33
Figure 3-2: A summary of the realization of the search 42
Figure 3-3: Example of how codes were applied to data during analysis 47
Figure 3-4: The main themes of the integrative literature review 48
Figure 4-1: Phase 2 - interviews and second point of interface 71
Figure 4-2: Main themes identified with interviews analysis and how they relate 80
Figure 4-3: Need for information: communication 83
Figure 4-4: Need for information: types of information and reasons 83
Figure 4-5: Need for parent-to-parent support 86
Figure 4-6: Need for professional support: counselling 87
Figure 4-7: Need for professional support: service coordinator 88
Figure 4-8: Need for professional support: accessible and approachable professionals 90
Figure 4-9: Need for professional support: professional services 91
Figure 4-10: Need for self-confidence in the care of the infant 94
Figure 4-11: Need for social support 97
Figure 4-12: Need for normality 99
Figure 5-1: Main themes of integrative literature review and interviews 103

LIST OF ADDENDUMS

ADDENDUM 2-1 120

ADDENDUM 2-2 122

ADDENDUM 2-3 124

ADDENDUM 3-1 125

ADDENDUM 3-2 126

ADDENDUM 4-1 136

LIST OF ACRONYMS

ADA	American Dietetics Association
CASP	Critical Appraisal Skills Program
CRD	Centre for Reviews and Dissemination
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
IDLE	Inductive and Deductive Logic Evidence
MRC	Medical Research Council
NICU	Neonatal Intensive Care Unit
NWU	North-West University
PICOT	Population of interest, Intervention, Comparison, Outcome, Timeframe
SANC	South African Nursing Council
WHO	World Health Organization

Chapter 1: Overview of the study

1.1 INTRODUCTION TO THE CHAPTER

The aim of this study was to explore and describe the support needs of parents of infants with complex health needs in a South African community. Literature has discussed the importance of supporting these parents in caring for their children (Dunst, 2000:99; Farmer *et al.*, 2004:362; Johnston *et al.*, 2004:360,362; Van der Walt, 2006:103-104), as this has a big impact on the well-being of the parents as well as the child. These families need special attention in health care and the identification of their needs will assist the multidisciplinary team in supporting these families in the community.

1.2 BACKGROUND TO THE STUDY

Over the last twenty years advances in the field of medical technology, medicine and health care increased the survival rate and life expectancy of infants with complex health needs (Mori *et al.*, 2011:111; Nishida & Oishi, 1996:252-254; Riley *et al.*, 2008:160-161; Yu & Doyle 1996:260). These infants and children with a wide range of disabilities and chronic conditions are mainly cared for at home (Glendinning *et al.*, 2001:324; Heaton *et al.*, 2005:443-445; Kirk *et al.*, 2005:458; While *et al.*, 2004:209-211). This results in an increased number of these families seeking support in community settings (Kirk, 1998:103; Marlow *et al.*, 2005:11-13; Riley *et al.*, 2008:163).

As a background to this study this chapter will discuss the challenges parents face, the service quality and availability, and it will provide an overview of the study methodology.

1.2.1 PARENTING CHALLENGES

Any parents, especially first time parents have different sources of stress, such as difficulty knowing how to settle the infant, feeding the infant and conflicting advice from professionals (Eronen *et al.*, 2007:24). Parents of infants with complex health needs also experience these stressors, but with additional challenges in their daily lives, emotional well-being, physical environment, financial well-being, social well-being, obtainment of skills and their contact with services and professionals (Abbott *et al.*, 2005:231). For these parents to address their challenges involve receiving support from within their community. This support is an important resource that assists families to adapt to their new situation (Van der Walt, 2006:103-104).

Parents of infants with complex health needs need to learn new caring skills to adjust to their new role as parent *and* as care giver of their infant. Their needs are specifically related to

enabling them to care for their infants. It includes obtaining equipment, supplies and funding (Abbott *et al.*, 2005:231; Kirk, 1999:352-354; Kirk & Glendinning, 2004:214). Part of their new skills may be to perform certain medical or technical procedures and this entails gaining medical knowledge (Abbott *et al.*, 2005:231; Hobson & Noyes, 2011; Kirk *et al.*, 2005:460; Kirk & Glendinning, 2004:212-213; Minnes & Steiner, 2009:254), which can be distressing and has a big impact on their daily life and quality of life.

The daily lives of parents of infants with complex health needs are impacted by the amount of time they spend with the infant and the dependency of their infant on them (Hemming & Akhurst, 2009; Kirk & Glendinning, 2004:231). Kirk *et al.* (2005:460) describe that the participants of their study reported that being a parent and a care giver for their children at the same time is problematic. Some of them resented that the caring role overshadowed the parenting role, and they consequently struggled to have a parent-child relationship (Kirk *et al.*, 2005:460). One mother described how she could engage in normal parenting activities with her child between procedures, but this was disrupted when she had to perform procedures outside normal parenting activities like giving nasogastric feeds to her child (Kirk *et al.*, 2005:460). This role confusion has a big emotional impact on parents (Abbott *et al.*, 2005:233; Kirk *et al.*, 2005:460) and the constant caring for their infants may cause sadness, exhaustion, distress and isolation (Abbott *et al.*, 2005:233; Hemming & Akhurst, 2009; Hobson & Noyes, 2011; Kirk & Glendinning, 2004:213; Kirk *et al.*, 2005:460).

Parents of infants with complex health needs therefore experience emotional strain and stress, which is especially increased by poor coordination of services, having to care for their children 24 hours a day and performing nursing tasks above that of parenting (Abbott *et al.*, 2005:233; Kirk & Glendinning, 2004:212-213,215; Wood *et al.*, 2009:13). Unfortunately these parents experience little emotional support from professional, community or family structures (Abbott *et al.*, 2005:233; Hemming & Akhurst, 2009). Although spouses are described as important in providing emotional support (Baum, 2004:386; Kersh *et al.*, 2006:888-889), participants in a study on parents of infants with congenital heart conditions reported that it is difficult and sometimes time-consuming to provide emotional support to their partners or spouses (Svavarsdottir & McCubbin, 1996:211-212).

Change in the physical environment is often a challenge to parents. Parents may need to change their home to make it more accessible as the infant grows up or to allow for technical equipment (Abbott *et al.*, 2005:232; Buran *et al.*, 2009:91, Kirk *et al.*, 2005:459). Invasion of the home by medical personnel and equipment may lead to a sense of loss of privacy and transformation of the meaning of home – the home becomes medicalised (Kirk *et al.*, 2005:459).

These parents are frequently concerned about their finances. Children with complex health needs may have more medical related expenses and the time parents spend to care for their children may cause financial strain (Abbot *et al.*, 2005:232; Buran *et al.*, 2009:91; Glendinning *et al.*, 2001:328-329; Hemming & Akhurst, 2009; Kirk & Glendinning, 2004:213; Wood *et al.*, 2009:13). Health care related costs are for some parents a major source of stress (Svavarsdottir & McCubbin, 1996:212; Swartz, 2005:118).

Parents of children with complex health needs commonly experience social isolation (Abbott *et al.*, 2005:232; Hobson & Noyes, 2011). Some of the reasons for this isolation is the lack of social support from extended family members (Abbott *et al.*, 2005:233; Hemming & Akhurst, 2009; Hobson & Noyes, 2011), lack in child care options (Buran *et al.*, 2009:91; Hemming & Akhurst, 2009; Hobson & Noyes, 2011; Sloper & Turner, 1992:272) and difficulty to leave the home due to the complexity of the child's needs (Abbott *et al.*, 2005:232; Hobson & Noyes, 2011; Kirk & Glendinning, 2004:213). Dunst (2000:99) suggests the importance of social support as it directly influences the health and well-being of parents of children with complex health needs, which in turn affects the child's behaviour and development. According to literature, poorly perceived social support also leads to more unmet needs (Farmer *et al.*, 2004:362). Participants in the study of Abbott *et al.* (2005:232-233) expressed that their need to do things together as a family was very difficult to meet.

Parents of infants with complex health needs are in contact with several different professionals a year (Sloper & Turner, 1992:268), which is time-consuming and impacts on parents financially. A multidisciplinary approach to service provision can reduce the amount of appointments parents have with professionals (Abbott *et al.*, 2005:235), and a person who links services and professionals can be beneficial (Kirk & Glendinning, 2004:215). Still, participants of the study of Abbott *et al.* (2005:234) expressed that even having a person who can link services doesn't really make a difference if there is little resources available.

1.2.2 AVAILABILITY AND QUALITY OF SERVICES

It is well-recorded that parents of children with complex health needs report inadequate information on services available, although they have the need for this information (Buran *et al.*, 2009:89; Minnes & Steiner, 2009:252; Sloper & Turner, 1992:271; Wood *et al.*, 2009:13). Unfortunately, this is often related to few services available (Abbott *et al.*, 2005:234; Hemming & Akhurst, 2009; Wood *et al.*, 2009:13).

The availability of services is a challenge that South African parents also experience. This is evident from a study in Kwazulu-Natal where mothers of infants with complex health needs reported a lack of support and services (Hemming & Akhurst, 2009). This statement and the importance of early intervention was supported by the association Down Syndrome South

Africa, who warns that in the South African context these services are inadequate and neglected, that there are poor referral systems and follow-up after initial screening, and that diagnosis of disabilities may be delayed (Lloyd, s.a.). Finally, studies on infant hearing loss in South Africa reported few available screening services, leading to late diagnosis (Swanepoel *et al.*, 2009:785, Van der Spuy & Pottas, 2008:S32), even though parents showed a very positive attitude towards early detection and intervention in infant hearing loss (Swanepoel & Almec, 2008:S46).

Participants in a study on parental views regarding ways to enhance the quality of health care for their children reported that parents experience a lack of knowledge and interest in their children by health care professionals, making it difficult for parents to gain information on the care and support for their children (Minnes & Steiner, 2009:252-253). Barriers to accessing services were reported, like extensive travelling to clinics, the cost of health care, waiting periods to receive services, inappropriateness of services and delayed diagnosis of the child (Buran *et al.*, 2009:91; Hemming & Akhurst, 2009; Minnes & Steiner, 2009:252).

The participants of a study done by Mitchell and Sloper (2003:1068) indicated certain qualities that are important to any service rendered: meeting the child and family's needs, listening to both family and child and treating the child and family with respect. Staff should be knowledgeable and well-trained, welcoming, helpful and should demonstrate respect for the family's culture. Other indicators of quality services were accessible and written information, clear indication from services of who they serve, professionals working together, knowledgeable professionals, flexibility, reliability, availability, continuity of care and the opportunity to meet other parents (Hemming & Akhurst, 2009; Minnes & Steiner, 2009:254; Mitchell & Sloper, 2003:1068-1070).

In South Africa the guidelines proposed for the management of the developmental needs of infants are similar to the qualities reported above. It includes family-centred care, developmental care of infants as central focus, establishing resources and infrastructure, professional management and effective management of infants with developmental delays and disabilities (Leech *et al.*, 2007a:107). These guidelines are important as Bornman and Alant (2002:46) reported that in rural areas of South Africa referral of these infants are inadequate and compliance to referral low. Transport problems and financial difficulties of the care givers are largely known to contribute to this problem. One of the recommendations that were made is that the registered nurse who works in the community should be educated and knowledgeable in handling and treating children with severe disabilities as this will lead to quality, sustainable and direct service delivery (Bornman & Alant, 2002:46).

In South Africa there is a shortage of nurses, not all registered nurses are actively part of the workforce, and in the public sector there is an unequal distribution of registered nurses (Breier *et al.*, 2009:25; Daviaud & Chopra, 2008:47; Reagon *et al.*, 2004:21). The burden of disease should definitely also be considered an obstacle. In South Africa the high HIV/AIDS and tuberculosis incidence contributes to a shortage of time spent on infant development and investigating parents' concerns. This leads to poor identification, support, referral and follow-up of infants with complex health needs (Bornman & Alant, 2002:46; Breier *et al.*, 2009:26; Leech *et al.*, 2007b:97-98).

1.3 PROBLEM STATEMENT

From the background of this study it is apparent that parents of infants with complex health needs face many challenges, such as poor availability of services. As the primary care givers of their infants parents' support needs are specific and they consult a variety of professionals to try and meet these needs. However, the support needs of these parents are not clearly stated and contextualised for a South African context.

1.4 RESEARCH QUESTION

Emanating from the background and problem statement, the following question was formulated:

What are the support needs of parents of infants with complex health needs in the community setting in South Africa?

1.5 AIM AND OBJECTIVES OF THE STUDY

In order to answer the research question the main aim of this study was to explore and describe the support needs of parents of infants with complex health needs in the community setting in South Africa.

Objectives set to reach this aim were to:

1. Critically appraise and synthesise the best available evidence on the support needs of parents of infants with complex health needs;
2. Explore and describe the emic perspective on the support needs of parents of infants with complex health needs in a South African context.

1.6 SIGNIFICANCE OF THE STUDY

Many health care professionals are involved in the care of infants with complex health needs. As many of their roles overlap it may cause role confusion and therefore sometimes a lack of

participation in the care of these infants, especially for the registered nurse. A clear description of the support needs of parents of infants with complex health needs will contribute in role clarification of all members on the multidisciplinary team in their collaborative effort to support these parents in the community.

1.7 PHILOSOPHICAL FOUNDATION

The philosophical beliefs of the researcher influence how research is conducted, as epistemological and ontological assumptions guide methodology (Creswell, 2009:5; Mouton & Muller, 1998:2) and form the philosophical framework in which the research is embedded. Assumptions of the researcher influence the logic, development and design of the research (Burns & Grove, 2005:39) and therefore need to be recognised and acknowledged for the role they play in this study. The researcher's assumptions are explained below.

1.7.1 CENTRAL THEORETICAL ARGUMENT

Parents of infants with complex health needs who care for their infants at home have comparable support needs. These needs touch on many aspects of their lives and include educational, emotional, practical and social needs. An evaluation and synthesis of the available information on the support needs of parents of infants with complex health needs combined with an emic perspective of the needs of parents from a variety of centres in one of South Africa's larger cities, may lead to information that can be used by community health care workers to support these parents within their own world perspective.

1.7.2 META-THEORETICAL PERSPECTIVE

View of man (human being): I view human beings as holistic beings created uniquely by God. Development and maturation are influenced by both nature (genetics) and nurture (environment). Infants with complex health needs have the right to be nurtured to develop their full potential. The parents of these infants are primarily responsible for fostering this potential, but because of the infants' unique and complex health needs, parents will need support in actualising this responsibility.

View of society: Society creates the environment in which human beings function. For parents of infants with complex health needs society consists of family, friends, parents in similar situations and the medical team. Society is where these parents seek support, and it may either have a positive or negative influence on them. As a functional and supportive society is crucial to the parents of infants with complex health needs, it is important that society is educated on how to provide support for these parents.

View of health: I agree with the definition of World Health Organization (WHO) that "health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO, 2005:1) and that all should have the opportunity to attain full health without disadvantage (WHO, 1999:1). Therefore, a person with perceived unfulfilled needs is not healthy or independent. Parents and their infants with complex health needs also have the potential to attain their optimum health and quality of life.

View of nursing: I view nursing as a professional, caring discipline and science. This view acknowledges the nurse as an independent practitioner. The specialised knowledge nurses have about the populations (parents of infants with complex health needs) they serve enhances client well-being. Nursing research is therefore important in advancing and maturing the profession (Walker, 1992:3) and improving service delivery. Further, nursing is the prevention of disease and promotion and facilitation of optimum health for the individual, family and community (SANC, 1984:2). The nurse is therefore a facilitator assisting the client in achieving a perceived optimum state of health (Alligood & Marinner Tomey, 2010:546). The nurse has a unique role, although some of the functions are shared by other professionals, and parents of infants with complex health needs should have access to this unique function of the nurse.

My meta-theoretical perspective corresponds with that of the theorists of the theoretical framework of this study (refer to paragraph 1.7.3).

1.7.3 THEORETICAL PERSPECTIVE

This study sought understanding of the support needs of parents of infants with complex health needs as part of their reality and experience. The theoretical framework underpinning this study is the theory of modelling and role-modelling developed by H.C. Erickson, Tomlin and Swain (1983). This theory highlights similarities and differences between individuals using psychological, cognitive and biological theories as their basis for development, including the work of theorists like Maslow, Erik Erikson, Milton H. Erickson, Piaget, Engel and Selye (Alligood & Marriner Tomey, 2010:540-541). The modelling and role-modelling theory allows health care professionals to care for and nurture their patients as unique individuals with the focus on the patients' needs. The theory of modelling and role-modelling is not tested in this study, but rather underpins the necessity of exploring and describing the support needs of parents of infants with complex health needs.

The theory explains certain similarities between individuals:

Holism. This implies that people are more than the sum of their parts and that conscious and unconscious processes are equally important. Human beings are holistic with multiple, interacting subsystems (Erickson *et al.*, 1983:44-45). Health is thus a holistic state of well-being.

Lifetime growth. Basic needs for survival and growth motivates behaviour. Needs are only met if they are perceived to be met by the individual (Alligood & Marriner Tomey, 2010:542). According to this theory needs that are met no longer exist and growth has occurred, but needs that are left unmet interfere with holistic growth and can aggravate or lead to mental or physical illness. People are in a constant changing state and if given accurate information, social support and assistance to change as they desire, then they will make good decisions for themselves (Erickson *et al*., 1983:46).

Lifetime development. This consists of psychological stages and cognitive stages. Each psychological stage represents a development task (described by Erik Erikson). Individuals mature as they complete age specific tasks and gain strengths and virtues at each stage completed (Erickson *et al*., 1983:61). The cognitive stages are also sequential stages of learning in the individual.

Affiliated-individuation. This is a concept unique to the modelling and role-modelling theory, highlighting the dependence on support systems throughout life, but simultaneously maintaining an independence and freedom from these systems (Erickson *et al*., 1983:68). Attachment and loss form part of this concept and describe the individual's need to attach to an object in order to satisfy her/her needs repeatedly. Loss of these objects can lead to lack in coping and morbid grief.

Differences between individuals are also explained in the theory:

Inherent endowment. This is the genetic make-up of each individual, affecting growth, health and development (Erickson *et al*., 1983:74). This concept is what makes each individual unique.

Adaptation. This is the potential of the individual to cope with stress and respond to stress in a growth and health directed way. Internal and external resources for coping are mobilised to adapt and no subsystem of the individual is compromised in the process (Erickson *et al.*, 1983:47, 75). Maladaptation occurs when a subsystem cannot cope with a stressor and then compromises another subsystem, using it as a coping resource and leaving it vulnerable to stressors (Erickson *et al*., 1983:47).

Self-care. Self-care knowledge is a person's knowledge regarding what made him sick, what will make him better and what promotes his growth and health. Self-care resources are the internal and external resources to cope with stressors, maintain health and promote growth. Self-care action is the utilisation of self-care knowledge and resources (Erickson *et al.*, 1983:48). People react differently to stressors, and life events should be viewed individually from each person's own perspective (Erickson *et al*., 1983:84).

Each individual has a unique model of his own world and it is this model that the health care professional uses to create an image and understanding of the patient's world (Erickson *et al.*, 1983:94-95).The art is to develop a mirror image of the patient's world perspective and the science is to collect and analyse data about the patient's model (Erickson *et al.*, 1983:95). Role-modelling then occurs after data has been collected from the patient's world. It requires unconditional acceptance of the patient as a unique person. Interventions are planned and implemented that are unique to the patient and that encourage and nurture the patient for growth, health and development at his own pace and in his own model (Erickson *et al.*, 1983:95).

The similarities in context of this study therefore suggest that parents of infants with complex health needs have basic needs that should be understood from their worldview and if the needs can be met, illness can be avoided and growth can occur. Parents of infants with complex health needs will be dependent on support systems, while desiring to function independently of these systems. Parents of infants with complex health care needs will therefore be able to make good decisions for themselves and their infants if they receive accurate information, are assisted in change and receive social support.

The differences in the context of this study make the health care professional aware that every family and parent is unique and different. They will have their own way of coping, adapt differently and have different resources and ideas on how they can be supported better. It is important to recognise these differences and tailor a specific plan for each family that suits their situation and involves their self-care knowledge and resources.

This study therefore attempts to create a mirror image of the world of parents of infants with complex health needs, through describing their support needs. It will guide the health care professional on the support needs of these parents and thereby promote the health of these parents through relevant support. This study will also highlight the unique needs of these parents, which need to be fulfilled for lifetime growth and what they believe will be the best support for them according to their self-care knowledge.

1.7.4 METHODOLOGICAL PERSPECTIVE

Methodology is the "logic of social inquiry" (Mouton & Muller, 1998:2) and is influenced by the epistemological and ontological assumptions of the researcher. Thus, the methodological perspective of the researcher will influence the research design. The researcher of this study believes that an approach should be utilised that best answers the research question. This correlates with what Creswell (2009:10) describes as a pragmatic worldview, where the emphasis is on the research problem and how to understand it, instead of on the method. Creswell (2009:10-11) argues that specific characteristics of pragmatism provide a philosophical

basis for research: it is not committed to just one system of philosophy and uses both quantitative and qualitative assumptions, the researcher is free to choose his method, techniques and procedures for research, researchers look to many approaches to collect and analyse data, methods are implemented that provide the best understanding of the research problem, researchers look to the *what* and *how* to research and therefore establish a purpose for their methods and finally that research occurs within a certain context and this guides the research.

In this study the pragmatic worldview of the researcher led to the selection of a mixed method approach in order to understand the research problem best. A mixed method approach was necessary to understand the research problem in context of these parents' perspective, but also to provide a broader view on the support needs of parents of infants with complex health needs, where a single method study would have provided a restricted view of their support needs.

1.7.5 DEFINITION OF KEY CONCEPTS

1.7.5.1 Community

Community is a group of people who share some common important feature of their lives (Allender *et al.*, 2010:6). However, in this study community refers to the area where parents of infants with complex health needs live and function and will include their geographical area, their working area and where they receive medical care. Community therefore refers to being at home and in one's everyday living conditions.

1.7.5.2 Complex health needs

This refers to multiple health needs. These needs have also been described as special health care needs and involve infants with increased risk for or with chronic developmental, congenital, genetic, physical, mental or emotional disabilities or delays which demands health related services beyond that required by infants generally (McPherson *et al.*, 1998:138).

1.7.5.3 Infant

The first year of life, including the neonatal period, which indicates the first 4 weeks of life (Martin *et al.*, 2006:19-20).

1.7.5.4 Parental support needs

Refers to those interactions parents need to enable them to care optimally for their child at home (Kirk & Glendinning, 2002:627). This may relate to health information, emotional support, their social support network, technical or instrumental support and involvement with care (Kreutzer & Marwitz, 2008:4-5), but may include more as the support needs analysis unfolds.

1.8 RESEARCH APPROACH

A descriptive and explorative study was conducted as little research has been done on this topic in a South African context. Descriptive studies are designed to generate knowledge on a topic of interest without examining causality (Burns & Grove, 2005:232, Polit *et al.*, 2001:180). For this study a mixed method approach was followed, utilising an integrative literature review, which was followed by qualitative individual interviews with parents of infants with complex health needs to contextualise the findings of the integrative literature review for the community context within South Africa.

A sequential mixed method approach as described by Creswell (2009:213) and Morse and Niehaus (2009:48) was utilised to explore and describe the support needs of parents of infants with complex health needs by first evaluating and synthesising studies of high methodological quality through an integrative literature review (refer to Figure 1-1) . Then, an interview guide based on the findings of the integrative literature review was used for individual face-to-face interviews with parents of infants with complex health needs to provide an emic perspective on their support needs in a South African context. This study was therefore conducted in two consecutive phases where the findings of the first phase informed the data collection of the second phase (interviews). The results from both phases were integrated to answer the research question. Rigour and ethical considerations will be discussed in the next chapter.

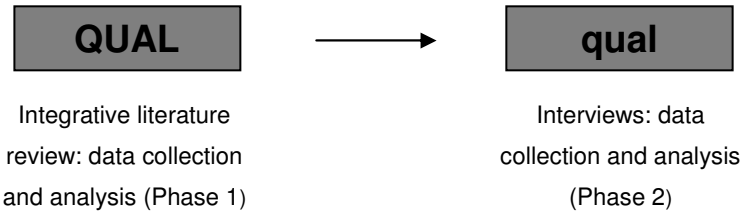

Figure 1-1: Sequential mixed method approach as illustrated by Creswell (2009)

1.9 OUTLINE OF THE STUDY

The dissertation consists of the following sections:

Chapter 1 Overview of the study

Chapter 2 Justification of research approach and methods

Chapter 3 Realisation of the integrative literature review

Chapter 4 Realisation of the interviews

Chapter 5 Evaluation, limitations and recommendations of the study

1.10 CONCLUSION

The number of infants with complex health needs increased over the last decades as medicine, nursing and technology improved. These infants are mostly cared for at home, often causing the parents stress and isolation resulting in a need for support to these parents in the community setting. This is also true for South Africa, where supportive services are scarce, especially in the rural communities, and the support needs of parents of infants with complex health needs are often not a first priority to health care professionals. Although some support is offered by certain institutions and professionals, the support can be improved dramatically if it is known exactly what these parents' needs are. Knowing these parents' needs may assist the multidisciplinary team in providing specific and unique support to parents in a way that is appropriate to their self-care knowledge and world-view.

Chapter two will justify the research approach and method utilised to explore and describe the support needs of parents of infants with complex health needs.

Chapter 2: Justification of research approach and methods

2.1 INTRODUCTION TO THE CHAPTER

In chapter two the research approach and methods will be described. Methods to ensure rigour and ethical conduct will also be discussed. The first phase of the study aimed at describing the support needs of parents of infants with complex health needs in the community, based on the best available research evidence. This information was then used to structure the interview guide to enable the researcher to validate the data within the South African context as the second phase of the study.

2.2 RESEARCH APPROACH

The research approach or design involves the overall plan of how the research will be conducted. It also includes the strategies to enhance the rigour of the study (Polit *et al.*, 2001:40,470). A mixed method approach was utilised for this study with two sequential components: the integrative literature review followed by individual face-to-face interviews.

Mixed method research usually utilises the strengths of both qualitative and quantitative approaches through data integration during the research process of a single study. It clearly differs from a multi-method study, which is two separate but related research projects (Morse & Niehaus, 2009:13). The mixed method approach is ideal for investigating complex problems in health care sciences (Creswell, 2009:203) and generates a better understanding of the research problem by incorporating complementary qualitative and quantitative methods. However, in this study the sequential mixed method design as described by Morse and Niehaus (2009:29) were followed where the core component (integrative literature review) was conducted first followed by the supplementary component (interviews).

This study design consisted of two qualitative components, a core component (QUAL = integrative literature review) and a supplementary component (qual = interviews). In the mixed method design the core component can stand alone and findings can be published without that of the supplementary component. The findings of the supplementary component, however, cannot be reported separately and are only used to enrich that of the core component (Morse & Niehaus, 2009:14). Although Creswell (2009) did not distinctly refer to this description, he praised the originality and usefulness of these concepts in his review on the back cover of Morse and Niehaus (2009).

In designing a mixed method study, different aspects are considered: theoretical drive, identification of the core component, pacing and point of integration. The choice of the core

component is influenced by the theoretical drive to be either qualitative or quantitative (Morse & Niehaus, 2009:24). The theoretical drive of the core component (QUAL) in this study is inductive. The integrative literature review as core component was a rigourous, systematic process which included both quantitative and qualitative studies for critical appraisal and synthesis. Whether the integrative literature review should be classified as qualitative or quantitative remains unclear. Based on the data being analysed qualitatively using thematic analysis, the decision was taken to classify it as a qualitative method. The core component of a mixed method study is the foundation of the study and the method that addresses the major part of the study (Morse & Niehaus, 2009:23).

The core component (QUAL) is enhanced by the supplementary component (qual). This concept is described by Creswell (2009:206) as weighting. The supplementary component is only conducted to the point where the researcher obtained the information needed (Morse & Niehaus, 2009:24). This is why Morse and Niehaus (2009:24) refer to the supplementary component as a strategy rather than a method. In this study the findings of the individual interviews with parents are supplementary to the findings of the integrative literature review in the sense that the participants were asked to comment on their experiences related to what was found in the literature on the support needs of parents of infants with complex health needs. This emic perspective puts these parents' support needs within the context of a South African community and contributes to the understanding of the support needs of parents of infants with complex health needs.

The interviews were conducted after the analysis of the integrative literature review, making this a sequential mixed method design (Creswell, 2009:213; Morse & Niehaus, 2009:17) with two distinct phases. This order refers to the pacing of the design, which is the synchronization or timing of the two methods used (Creswell, 2009:206; Morse & Niehaus, 2009:24). If the two methods are conducted simultaneously the design is concurrent, whereas it is sequential if the one method follows the completion of the other (Creswell, 2009:206).

Morse and Niehaus (2009:25) describe the integration of data as the point of interface, between the two phases of the mixed method approach. They argue that the point of interface can occur either during reporting of the data in the results section or, under strict conditions, during data analysis of the core component (Morse & Niehaus, 2009:25). Contrary to this Creswell (2009:211) do not refer to a point of interface but describes and argues that in a sequential design integration of data occurs when the results of the first phase *informs* the secondary data collection and that the data analysis of the second phase therefore builds on the results of the first phase.

In this study integration of data will be at two different points. First the findings of the integrative literature review informed the interview guide of the interviews. It will be referred to as the first point of interface. At the second point of interface the findings of the integrative literature review was integrated with that of the interviews during reporting of the findings of the interviews. Figure 2-1 illustrates both points of interface.

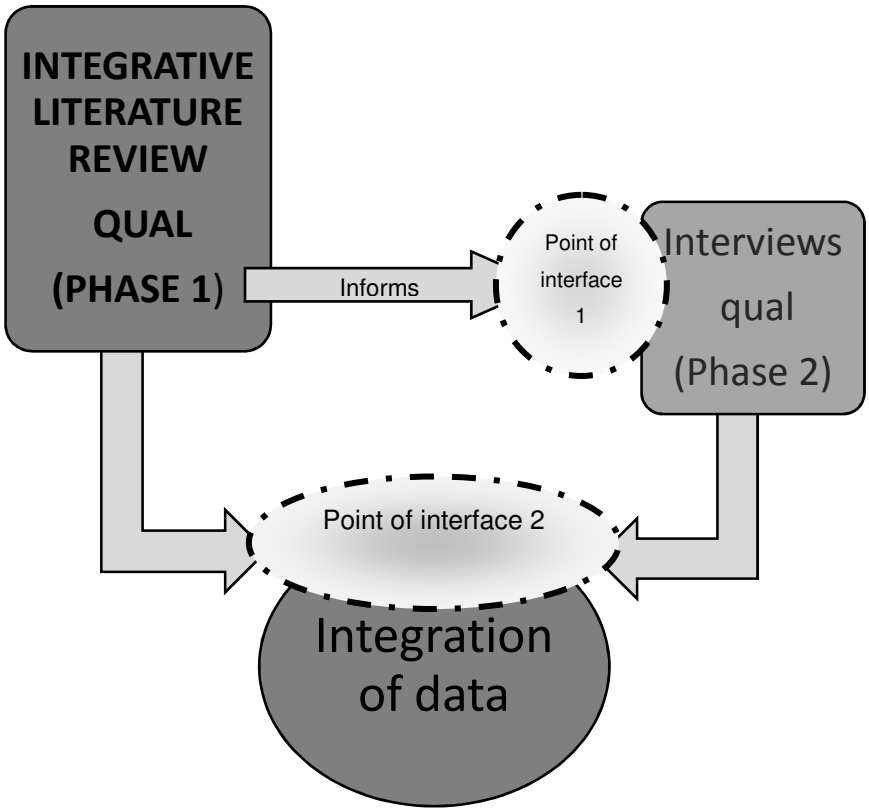

Figure 2-1: First and second point of interface

2.3 SETTING

Parents of infants with complex health needs take care of their children at home after they have been newly diagnosed or have been discharged from hospital. The infant at this stage no longer receives formal care by health care professionals at a hospital, meaning that these parents become the main care givers of their infants. They have to deal with different challenges like daily care giving tasks usually performed by nurses, emergency situations, administration of medication, learning how to use medical equipment and physical stimulation of the infants (Abbott *et al.*, 2005:232-233; Kirk, 1999:352-353). In this study the focus is on parents of infants

below one year of age, as this is usually when parents realise that their infant has complex health needs. This realization leads the parents to an investigation for a diagnosis. After the first year the parents already had a chance to deal with the diagnosis, find support and adapt to the new situation (Lowes *et al*., 2005:259). The focus of the study is therefore on the support needs of parents of infants with complex health needs during the first year of life when support is critical and they have to cope with the care of their child at home.

2.4 RESEARCH METHODS AND PROCEDURES

The methods used in this mixed method study to answer the research question was an integrative literature review (QUAL) followed by qualitative individual face-to-face interviews (qual) with parents of infants with complex health needs to contextualise the findings and formulate concluding statements embedded in the best available literature and the emic perspective of the participants.

2.4.1 INTEGRATIVE LITERATURE REVIEW AS METHOD OF CHOICE

With the preliminary scanning of literature on the support needs of parents of infants with complex health needs, little evidence was found on the support needs of these parents in a South African context. Still, research has been done internationally and therefore health care professionals can benefit from a holistic synthesis of the current, multidisciplinary literature to make it evident what is exactly known on this topic. The integrative literature review is an important method for establishing the current knowledge on the support needs of parents of infants with complex health needs by reviewing, critiquing and synthesising representative literature on the topic (Torraco, 2005:356).

Complex health needs arise from a wide variety of illnesses and disabilities. A synthesis of studies of high methodological quality will combine these studies and cover a range of different complex health needs, therefore describing the shared support needs of parents and not only the support needs that are unique to the infant's condition. As the integrative literature review is the broadest type of review method and combines qualitative and quantitative research (Whittemore & Knalf, 2005:547), it will allow for the combination of a variety of studies on the support needs of parents of infants with complex health needs.

Other methods of reviewing and synthesising research evidence are also available. Methods used to summarise qualitative research include meta-synthesis, formal grounded theory and meta-ethnography. These methods review and synthesise primary qualitative findings with different approaches and interpretation and may enhance the generalisability of the studies (Whittemore & Knalf, 2005:547). These methods were not suitable for this study as they only

allow for the synthesis of qualitative studies and will therefore exclude relevant quantitative studies from the review.

Systematic reviews combine the evidence of multiple primary studies and are usually the method of choice to inform evidence based practice (Whittemore & Knalf, 2005:547). The studies are all on a specific clinical problem and require a systematic approach and a comprehensive search of the literature. Different statistical and quasi-statistical approaches are employed to combine the studies. This review method traditionally utilises randomised controlled trials only and is therefore not a suitable choice for this study.

Some systematic reviews include a meta-analysis. A meta-analysis combines the overall findings of multiple primary studies through statistical analysis (Burns & Grove, 2005:115-116; Whittemore & Knalf, 2005:547). To do this, the research design, hypotheses, methods and data of these studies need to be very similar. Meta-analysis enhances the validity of findings by combining the evidence and allows for adjustment of sample size and study quality (Whittemore & Knalf, 2005:547). Again this method will exclude a variety of studies from the review and will therefore not provide a broad view on the support needs of parents of infants with complex health needs.

Considering all available review methods, the integrative literature review is the method of choice for this study. In searching for relevant studies databases were purposively selected on the grounds of its primary scientific focus. The integrative literature review will further appraise the quality of the studies included and synthesise and summarise the findings from qualitative and quantitative studies (Burns & Grove, 2005:226; Whittemore & Knalf, 2005:547). Synthesising these findings will allow for providing a broad picture of the support needs of parents of infants with complex health needs. In the context of this study the integrative literature review is typed as a 'mixed method review' as it is combined with interviews to reach a conclusion and to provide a more complete understanding of the research problem (Grant & Booth, 2009:98).

2.4.2 THE INTEGRATIVE LITERATURE REVIEW PROCESS

The integrative literature review follows a systematic process based on the process of the systematic review. The process is diligent, well-structured and safe-guarded against bias. The integrative literature review involves five steps: formulation of the review question, search strategy, critical appraisal, data analysis and synthesis and concluding statements, which is also referred to as conclusion statements by the American Dietetics Association (ADA). It is important to have a clear identification of the purpose of the review as this will facilitate all steps of the review process. This is especially true for the data extraction step, as studies with a variety of purposes, variables and settings will be reviewed (Whittemore & Knalf, 2005: 548). A

clear purpose will therefore guide the data extraction. Table 2-1 describes each step of the integrative literature review and the tools used in each of them to provide an overview of the process.

Table 2-1: The steps of the integrative literature review

Step	Description	Tools used in this step	Reference
Step 1	Formulating the review question	PICOT (ADA, 2010:16)	Paragraph 3.2.1 Table 2-2
Step 2	Search strategy *6 stages*	Purposive multi-stage search	Paragraph 3.2.2 ADDENDUM 3-1
Step 3	Critical appraisal	Checklist for assessing quality of quantitative studies from Kmet *et al.* (2004:4) Critical review form – qualitative studies from Letts *et al.* (2007)	Paragraph 3.2.3 Table 3-2 ADDENDUM 2-1
Step 4	Data analysis and synthesis *Thematic analysis*	Creswell (2009:184-189)	Paragraph 3.2.4
Step 5	Concluding statements	IDLE-method™	Paragraph 2.4.2.5

The process of the integrative literature review is discussed in this chapter according to the steps followed.

2.4.2.1 Formulating the review question

The first step in the integrative literature review was to formulate a review question that is relevant to the research problem and purpose of the study. A well-formulated review question is essential for a good integrative literature review and focuses the review purpose (Centre of Reviews and Dissemination [CRD], 2009:3; Evans, 2007:140; Whittemore & Knalf, 2005:548). A review question therefore needs to be clear and focussed to guide the search without excessively limiting it (ADA, 2010: 16).

PICOT is a useful structure to use as a systematic approach in formulating the review question. PICOT is known as: population of interest (P), interventions (I), comparative intervention (C), outcomes to measure (O), the timeframe (T) and the setting or study design (S) (ADA, 2010:16; CRD, 2009:8; Newhouse *et al.*, 2007:55).

The population of interest in this study is parents of infants with complex health needs who care for their infants at home. The population of interests is therefore closely related to the setting, which is in the community setting. This is a non-intervention study and there are no intervention or comparison variables to identify. Lastly, the outcome is to identify the support needs of these

parents when their infants is under one year of age, which is the timeframe variable. Table 2-2 delineates the variable of the research question according to the PICOT format.

The following review question was formulated by utilising the PICOT format:

What are the support needs of parents in the community with infants with complex health needs that are under the age of one year?

Table 2-2: Variables of the research question

Population	Intervention	Comparison	Outcome	Timeframe	Setting
Parents of infants with complex health needs	Not applicable	Not applicable	Support needs identified	Infants under the age of one year	In the community

This review question directed the search strategy aimed at the support needs of parents of infants with complex health needs in the community.

2.4.2.2 Search strategy

The second step involved formulating the search strategy and describing the technique used to search the literature and screen for relevant studies. A search of this nature should be comprehensive, using different databases, keyword combinations and grey literature such theses, dissertations and unpublished studies. Exclusion and inclusion criteria were defined in order direct the search to high quality and relevant studies (Whittemore & Knalf, 2005: 549). A scoping search of the literature was done to refine the search strategy and identify relevant key words for the search.

a. Study population

The study population for the integrative literature review included all research studies that complied with the inclusion criteria on the needs of parents of infants with complex health needs. The unit of analysis was both quantitative and qualitative research studies.

b. Key words

The search was started with a scoping search to get a sense of the current literature and embed the researcher in the topic. This scoping search revealed the research already conducted on this topic, the methods used to research it and possible key words used.

Key words used in the scoping search were broad and included parent, baby, infant and special needs. The scoping search revealed prevalent terminology used when describing these infants, including medically fragile, complex health needs and disabled. Based on the scoping search the following key words were identified (Evans, 2007:141): parent* need*, infant*, baby (bab*), complex health, medical*, fragile, disability (disab*), support, special. [1] The search strategy and key words were discussed and concluded with the study supervisors and independent reviewer and with guidance from a librarian.

c. Inclusion criteria

Selection criteria are important to determine the boundaries and scope of the review (Evans, 2007:140). All research studies published in scientific journals on the support needs of parents of infants with complex health needs under the age of one year, post-discharge from hospital, published between January 1986 and 31 October 2011 were included. The scoping search showed that the majority of relevant journal articles appeared in the databases from 1986.

d. Exclusion criteria

- Articles relating to parents during the Neonatal Intensive Care Unit (NICU) stay of their infant only.
- Articles not based on primary research.
- Duplicated articles.
- Editorials or letters to the editor.
- Books will be excluded from this review since they are regarded as secondary sources of information.
- Irrelevant studies, not specific to parents of infants with complex health needs.

e. Search process

Multi-stage search means that each stage of the search follows the previous stage, where each consecutive data source was searched for studies not included in the previous stages, thus following an accumulative search process. Using different data sources and a wide range of search terms prevents publication bias and increases the possible number of relevant articles found in the search (Shaw *et al.*, 2004).

[1] *Note: * means that any form of the word will be searched, for example parent* can be parents, parental, parenting, etc.*

A multi-stage, purposive search strategy was used:

- Stage 1: Electronic databases were searched through platforms using the appropriate search words.
- Stage 2: Specific databases not included in the previous sample were searched from an electronic catalogue. Utilising a catalogue organises the search and ensures that all available data sources are sampled.
- Stage 3: Journals were searched through the library catalogue of journals for articles not available electronically.
- Stage 4: Pubmed and Google Scholar were searched additionally.
- Stage 5: The electronic searches were followed by searching for studies in the reference lists of the studies already identified in the previous data sources.
- Stage 6: Lastly a prominent, published author on the research topic was contacted via e-mail.

The articles that met the inclusion criteria were then critically appraised to evaluate the methodological quality of the studies as only studies of high methodological quality were included in the review.

2.4.2.3 Critical appraisal

Through critical appraisal the researcher purposively reviewed each article for its methodological quality and included rigour of the selected research studies. The critical appraisal ensured that only studies of high quality were included in the integrative literature review, strengthening this study's rigour. Two instruments, that of Letts *et al.* (2007) and Kmet *et al.* (2004), were used to evaluate the methodology of quantitative and qualitative studies. An independent reviewer reviewed the studies with the researcher and consensus was reached on the strength of evidence rated.

The two instruments that were considered to critically appraise qualitative studies were the Critical Appraisal Skills Program (CASP) instrument for qualitative studies and a qualitative critical appraisal instrument developed by Letts *et al.* (2007). The instrument from Letts *et al.* (2007) contains more in-depth and specific questions related to the study appraised and is therefore more suitable and comprehensive to use in this study for critical appraisal of qualitative studies. Using only one instrument ensured consistency during critical appraisal.

For the same reason a general quantitative critical appraisal instrument was used to appraise quantitative studies. The critical appraisal instrument used for the quantitative studies was the checklist for assessing the quality of quantitative studies from Kmet *et al.* (2004:4). The

instruments used for critical appraisal was chosen by the reviewer and the independent reviewer and confirmed with the supervisors of this study.

Grant and Booth (2009:94) suggest that the integrative literature review in the context of this study should have a generic appraisal instrument or instruments with corresponding checklists. Generic qualitative and quantitative instruments were chosen (refer to ADDENDUM 2-1). The studies meeting the inclusion criteria were critically appraised and graded according to the grading system of ADA and only those of good methodological quality were then included for data extraction, analysis and synthesis.

2.4.2.4 Data analysis and synthesis

Analysing data includes ordering, categorising, reducing and summarising the findings of the included studies to make it interpretable. It is a continuous process that leads to conclusions related to the research question. The goal is to develop a summary based on interpretation of the included studies (Whittemore & Knalf, 2005: 550).

A six step process described by Creswell (2009:184-189) was used to analyse and synthesise the data: organise and prepare data, identifying patterns of meaning, coding of data into meaningful units, discussion of themes, presentation of data and interpretation of data. Data extraction was done according to author, year of publication, the study method, sample and the key findings related to support needs of parents of infants with complex health needs. The extraction of data gives a summary overview of the studies included for data analysis. Data in this integrative literature review refers to the findings of the primary studies related to the support needs of parents of infants with complex health needs and was analysed using the thematic analysis method.

Thematic analysis is one of the most common analytical methods in qualitative studies and requires identification of repeated and prominent patterns of meaning in the body of data, followed by a detailed description of the findings of the studies under these themes (Braun & Clark, 2006:79; Pope *et al*., 2007:96). Thematic analysis has many advantages, including that it is flexible, can summarise a large body of evidence and reflect the similarities and differences in the data (Braun & Clarke, 2006:97). This made it the ideal method for synthesising qualitative and quantitative data from the included studies.

A discussion of each theme synthesised the related findings of the primary studies and were concluded in the form of concluding statements.

2.4.2.5 Concluding statements

A concluding statement is a final and overall conclusion of the integrative literature review based on the findings of the reviewed studies. It answers the review question and should be clear, direct and concise (ADA, 2010:59) and consider findings that correspond and differ, as not all findings will support the review question. The conclusion is a summary of the evidence only (CRD, 2009:82) and was presented in the form of statements with clear links to the studies included. This is ensured by using the IDLE-method™ as a process of logic reasoning to form conclusions from the literature.

The IDLE-method™ refers to 'inductive and deductive logic evidence' a concept coined by Klopper and discussed in the study of Lubbe (2009:260). It assumes that correct and incorrect reasoning can be distinguished from each other through presented arguments. The reasoning process is provided in the discussion of each theme and strengthens the rigour of this study.

2.4.2.6 Rigour of the integrative literature review

Rigour refers to precision, thoroughness and openness in all stages of the research (Burns & Grove, 2005:33, 55) to ensure that the findings of the study are the truth and that bias is reduced. Whittemore (2007:151) suggests systematic methods, evidence of critical appraisal and transparency as criteria for enhancing rigour in an integrative literature review.

Through identifying applicable variables and formulating a review question an accurate and comprehensive search strategy was developed. A comprehensive search was essential in enhancing the rigour of this study through reducing bias by including representative, relevant studies in the search (Whittemore, 2007:151). The search should be as comprehensive as possible and include grey literature and studies in all languages in order to reduce bias (CRD, 2009:12; Hopewell *et al.*, 2005:50-55). Therefore the search for this review was comprehensive and included the search of electronic databases, journals not available electronically, databases for dissertations and theses, reference lists from studies and contact with prominent researchers in the field of interest.

Grey literature, such as theses, dissertations and unpublished studies, was included in the search. Including them in the search reduced publication bias together with the comprehensive search. English abstracts were available for all studies with relevant titles. However, none of the studies in languages other than Afrikaans or English were suitable for inclusion in the review and were consequently excluded. Therefore, although the reviewers were not fluent in languages other than mentioned, this did not lead to bias in the inclusion of studies.

In order to develop and refine the search strategy and key words for use in the search an initial scoping search was done during development of the review protocol. The researcher communicated with the supervisors during all the steps of the integrative literature review to ensure a rigourous search strategy and to guide decisions made. An experienced librarian was consulted on the key words used for search. Stipulated inclusion and exclusion criteria further enhanced the rigour and directed the search to relevant studies (Evans, 2007:140).

All studies meeting the inclusion criteria were critically appraised by two reviewers to ensure that only studies of high methodology quality were included in the review. Evaluating the quality of the studies increased the credibility of this study (Whittemore, 2007:152). Data were then extracted in a table, which facilitates organisation of the data and visualisation of the comparison of the primary studies selected for the review (Whittemore, 2007:152).

An independent reviewer is important in reducing bias of the review and was involved during the multi-stage search in refining the key words and ensuring that all relevant databases were searched, in critiquing and grading studies for data analysis and with development of the themes during data analysis. The independent reviewer is a researcher experienced in doing systematic reviews and assisted reviewing of several studies.

Evaluation of data was important in ensuring that only high quality sources were used for analysis (Whittemore & Knalf, 2005:550) and was done through the critical appraisal of studies with reliable appraisal instruments (CRD, 2009:10). The selected studies were consistently scored according to quality criteria instruments (refer to paragraph 3.2.3), allowing only for good methodological quality studies to be included for analysis. Inclusion of high quality studies improved the reliability of the findings. Scoring of the studies was done by two independent reviewers and the scores allocated to the studies by the reviewer correlated with that of the independent reviewer, enhancing the reliability of the results. Studies included for analysis were agreed upon by the researcher, supervisors and independent reviewer.

Thematic analysis was an appropriate analysis method for the review and two reviewers were involved in analysis to minimise bias (CRD, 2009:4). During analysis the researcher and independent reviewer agreed on data extraction and argued and adjusted themes until consensus was reached. Interpretation of the data was supported by quality data from the integrative literature review and therefore enhanced the validity of the study. The independent reviewer also gave input during the formulation of the concluding statements to ensure that it is a true reflection of the data analysed.

Transparency or auditability is important to enhance the rigour of this study (Whittemore, 2007:153) and was ensured by keeping a clear audit trail. Auditability is part of the study's methodological congruence (Burns & Grove, 2005:629). The audit trail of this study makes each

step of the integrative literature review clear and explains decisions made. The audit trail enables an independent researcher to follow the same procedures and increase the chance of arriving at the same conclusions, given the same primary studies, as the first researcher. An audit trail ensures that all readers understand how the conclusions were reached. Transparency was further enhanced by making clear the limitations of this study specifically in chapter five, but also as they arose while conducting the study.

Auditability further ensures the confirmability of this study (Polit *et al.*, 2001:316) by allowing an independent researcher to understand how data was collected and interpreted. Documentation related to the audit trail is the search strategy and the results of the search, the selection of the studies, critical appraisal of the studies for the review, data extraction from the studies and reference to the literature during data analysis and synthesis.

Internal validity relates to the neutrality and confidence in the truth of the research and can be threatened during data collection, data analysis and choosing of a population and sample (Polit *et al.*, 2001:312; Botes, 2003:178). Strategies like utilising a comprehensive search strategy and an independent reviewer and keeping an audit trail reduces threats to internal validity. Table 2-3 summarises the strategies to enhance rigour at each step of the integrative literature review.

Table 2-3: Summary of strategies used to enhance rigour of the integrative literature review

Steps	Strategies to enhance rigour	Rigour criteria enhanced
Formulating the review question	Identifying applicable variables	Systematic methods
Search strategy	Scoping search done Comprehensive search Including grey literature Relevant key words used for search Selection criteria set Audit trail kept	Systematic methods Transparency Auditability Transparency Confirmability
Critical appraisal	Two reviewers involved Utilising appropriate critical appraisal instruments Audit trail kept	Evidence of critical appraisal Auditability Transparency Credibility
Data analysis and synthesis	Included only studies of high methodological quality Supporting interpreted data with literature Independent reviewer involved in analysis	Systematic methods Transparency Validity Credibility
Concluding statements	Supported by studies of high methodological quality	Transparency Credibility

2.4.3 FIRST POINT OF INTERFACE

At the first point of interface (refer to Figure 2-1) the findings of the integrative literature review informed the interview guide for the interviews. Utilising the findings of the integrative literature review to structure the interview guide will ensure that participants can discuss their support needs in relation to the findings of the integrative literature review.

2.4.4 INTERVIEWS

The concluding statements of the integrative literature review may be unclear with regard to the applicability for the South African context, therefore individual face-to-face interviews were utilised to gain data (Poggenpoel, 2003:148). The data gained from the interviews contextualised this research study for a South African community.

An interview is a conversation between the researcher and participant that attempts to understand the participant's point of view and experiences in order to produce knowledge (Kvale & Brinkmann, 2009:1-2). In this study the individual interviews had the specific objective to explore the emic perspective of the participants on the concluding statements from the integrative literature review in order to understand the support needs of parents of infants with complex health needs in a South African context (Polit *et al.*, 2001:265).

A focus group interview was considered as group dynamics of a focus group interview helps individuals to express their thoughts and opinions more freely (Burns & Grove, 2005:542), thereby enriching the dialogue and the data collected (Polit *et al.*, 2001:265). However, selecting participants from different social backgrounds for this study and placing these participants in the same group may hinder discussion and expression of opinions. Thus, several individual interviews seemed more appropriate for the collection of data.

The individual interviews focused on specific themes without being strictly structured, and it used open-ended questions to guide the participants (Kvale & Brinkmann, 2009:31). The interviews were therefore open discussions that focussed on the support needs of eight parents related to the findings of the integrative literature review.

2.4.4.1 Recruitment

Participants were recruited from several centres for infants with complex health needs in one of the larger cities of South Africa. This city provides a large area with different communities, which can strengthen the representativeness of the sample. Although the centres were located in specific areas, clients attending these centres come from a broader geographical area.

Participants from different socio-economic and cultural backgrounds and who utilise different health care systems (private and government) were interviewed. All participants were parents of infants with complex health needs who take care of their infants at home.

2.4.4.2 The sample

During interviews the participants are regarded as experts. It is therefore necessary to purposefully choose participants who have extended knowledge and experience on what it means to be a parent of an infant with complex health needs (Creswell, 2009:178; Poggenpoel, 2003:150). Thus, parents were sampled using purposive sampling. Purposive sampling is the selection of participants who are information-rich and the best sampling technique to use when a new topic is explored in qualitative research (Burns & Grove, 2005:352).

As the interviews are the supplementary component of this study it is not necessary to reach data saturation (Morse & Niehaus, 2009:24) when no new data emerged. Interviews need only to be done until the objective is reached. Still, an initial sample of eight was theoretically specified by the researcher and the supervisors as adequate in representing diversity (Francis *et al.*, 2010:1234).

2.4.4.3 The interview process

The steps of the interview process included arranging the interview, establishing a contractual relationship with the participants, the actual interviews and the interview guide.

a. Arranging the interviews

A time convenient for the participants was arranged to conduct the interviews and the location and length of the interviews were also considered in arranging the interviews. The interviews were conducted at different locations including the participants' workplace, home or during a clinic visit. The length of the interviews ranged from less than 30 minutes to just under an hour. The next step in the interview process was to establish a contractual relationship with the participants.

b. Contractual relationship with the participants

During this step the research purpose was explained to the participants. Each participant signed a written consent form to participate in this research study and gave permission that the interview may be voice recorded (refer to ADDENDUM 2-2).

c. The interviews

Eight focussed interviews were conducted, covering certain areas of discussion through open-ended questions. The topics discussed centred on parental support needs and emanated from the concluding statements formulated in the integrative literature review. The interviews were voice recorded. Notes were also taken after each interview on the interview content (Creswell, 2009:183). These are known as field notes and were especially useful as some of the recordings were of poor quality.

The interviews were conducted by the researcher. The researcher was trained in and obtained some experience in conducting interviews during her under- and post graduate studies. The researcher consulted with experienced researchers on all the steps of the interview process and the pilot interview was evaluated by the supervisors.

d. Interview guide

The interviews were initiated with the question: "Can you please describe your most important need as parent in caring for your child?" After a discussion of this topic, themes from the integrative literature review were presented to the parents. They were told that these themes emerged from other research and asked whether they could relate to these needs. The themes discussed during the interview developed from the concluding statements of the interview and will be discussed in paragraph 4.4.4.

In an effort to enhance the flow of the discussion during the interview, questions in the interview guide were written in full. Suggested questions to ask under the main themes were constructed beforehand, but derived from the integrative literature review (King & Horrocks, 2010:40). Except for the first question, the sequence of the following topics or questions were not strict or predetermined (Kvale & Brinkmann, 2009:130) and was rather guided by the participants' response.

e. Transcription of the interviews

The voice recorded interviews were transcribed verbatim and both the transcripts and the field notes were used for data analysis.

2.4.4.4 Field notes

Field notes are notes taken during or after the interview on different aspects of the interview (Botma *et al.*, 2010:217) and serve as a written record of non-verbal behaviours and events during the interview that impressed the researcher (King & Horrocks, 2010:47). In this study the field notes were used for verification of the data (Botma *et al.*, 2010:217) to ensure a true

reflection of the interviews and were taken to place the interviews in context in order to report the interviews truthfully.

Polit *et al.* (2001:283) categorise field notes according to their observational purpose: *observational notes* on the setting of the interview, *theoretical notes* are interpretive on the meaning of the observations, *methodological notes* on the method or strategy of observation and *personal notes* on the personal feelings of the researcher. It is described by Creswell (2009:181-182) as descriptive and reflective notes and were taken after the conclusion of each interview.

2.4.4.5 Analysis of the data

In this study the results from the integrative literature review served as an analytical framework for the analysis. As the interviews were conducted to contextualise the findings of the integrative literature review, the themes developed in the integrative literature review was an appropriate framework for analysis of the interviews.

Creswell (2009:185-189) suggests six steps for analysing qualitative data. These steps were followed in analysing the data from the interviews. *Step one* involved organising the data by transcribing the interviews and typing up the field notes. During *step two* the transcripts were read and re-read to get a sense of the whole. *Step three* was the beginning of coding. Coding involved organising the data from the interviews into segments of text and organising them into the analytical framework. During *step four* the themes were further refined and supported with quotes from the transcripts. During this step the new theme identified were also labelled and described. *Step five and six* were combined as the representation and interpretation of the analysis during a discussion on the findings of the interviews. During these steps the findings were conveyed through a narrative passage and supported with literature from the results of the integrative literature review.

Data analysis from the interviews was a continuous process that already started during data collection; meaning that data analysis was started before all data was collected and this ensured a better understanding of the data by the researcher (Creswell, 2009:184; Liamputtong, 2009:134). Cross-case analysis was also conducted by comparing various data from different interviews with each other, looking for similarities, but also contradicting statements.

2.4.4.6 Rigour of the interviews

During the interviews the participants were regarded as experts on the topic discussed and information collected were considered to be true, but the researcher still applied specific measures to ensure that the information obtained was accurate and trustworthy.

Firstly, the researcher voice recorded each interview to enable her to listen to the interviews afterwards. It was also important to allow the researcher to reflect on each interview and adjust her interview technique as needed. The recorded interviews were also transcribed and field notes were taken with each interview to gain better insight into the setting and the experience of the researcher during the interview.

Secondly, the researcher attempted to approach the interview without preconceived ideas. This was difficult as the researcher did want to discuss specific issues with the participants based on the concluding statements of the integrative literature review. Still, she allowed the participants to lead the direction of the conversation. The same interview guide was used for each interview. This interview guide was first tested with a pilot interview. The pilot interview was then discussed with the study supervisors and no changes were made to the guide, but the researcher was encouraged to refine her interview techniques.

Transferability relates to the applicability of the research and is ensured through data saturation and a thorough description of the contexts and participants (Botes, 2003:181-182). By giving a description of the context, the participants and the interview setting, readers can judge the similarity of contexts and whether the findings of this study are transferable (Koch, 2006:92).

As the interviews were only a strategy that served as supplementary component to the integrative literature review, data saturation was not attempted (Morse & Niehaus, 2009:24). Still, interviews were not stopped prematurely, but the interviews were analysed for similar and also contradicting themes to ensure data were collected to the extent where it could supplement the integrative literature review. All themes analysed were agreed upon by the researcher and independent reviewer. Transferability was also enhanced by triangulation of findings from the integrative literature review and interviews and by maintaining a well-documented audit trail through referencing the applicable interview transcripts during data analysis (Finfgeld-Connett, 2010:249-250).

2.5 ETHICAL CONSIDERATIONS

The researcher is committed to ethical research and acted honestly, complied with ethical standards and considered ethical practices through all the stages of the research. Ethics in health research sets the values and norms that guide the research to benefit the patients and prevent suffering (Medical Research Council [MRC], 2003:13). Several ethical principles were considered during both the integrative literature review and interviews.

This study was considered for relevancy according to the need of the community studied and improvement of health in South Africa (Department of Health, 2004:3). Research of good scientific quality was conducted and careful planning with high standards of implementation and

reporting was honest and transparent. For the research to be accurate and conducted with competency, the researcher consulted with her supervisors on all steps of the research process and conducted the research with compassion and empathy (Department of Health, 2004:3). Data sources were handled with responsibility and are traceable through detailed record keeping, thereby ensuring auditability (Burns & Grove, 2005:629). Plagiarism was avoided by giving credit when it was due in the text and reference list. The researcher intends to share the findings of the research results through publishing the study results and presenting the research at a conference.

Kvale and Brinkmann (2009:63) state that there are ethical considerations at seven research stages when conducting interviews. These stages are thematizing, designing, interview situation, transcription, analysis, verification and reporting.

Thematizing. The purpose of this study was to explore and describe the support needs of parents of infants with complex health needs. This is not just to gain knowledge, but to improve the situation of the population through this knowledge.

Designing. Written, voluntary, informed consent was obtained from the participants before the interviews were conducted. Their confidentiality, privacy and right to withdraw from the study at any time were respected. The selection and inclusion of participants for this study was just and fair and not based on race, gender, level of education or religious beliefs (Department of Health, 2004:5). The right to self-determination and informed consent allowed participants to voluntarily choose to participate in the study and to withdraw from the study at any stage (Burns & Grove, 2005:181). The participants were fully informed on what the aim of the study was and what it entailed, therefore ensuring transparency. Although complete anonymity cannot be kept in an interview, the participants were anonymous in reporting the data collected (Burns & Grove, 2005:188). Confidentiality of participants was also protected by safe-guarding the raw data against unauthorised individuals through password protected files on the computer. The informed consent form is available in ADDENDUM 2-2.

Interview situation. The personal consequences of the interview for the participants were considered and during the interview the participants were handled with empathy and allowed to avoid topics that were too sensitive for them.

Transcription. The transcribing was done by an individual who understands and values anonymity and ethical values. As the researcher conducted all the interviews herself and took field notes, the transcribed text could be seen within the context of the interview itself. It is therefore true to the oral statements of the participants.

Analysis. Although the participants did not have a say in how their statements were interpreted, thematic analysis was done on the content of the interviews only and the deeper meaning were not sought or reported on.

Verification. As the interviews were conducted as a supplementary component of the mixed method study, the results of the integrative literature review verified the findings of the interviews.

Reporting. No participant is identifiable from the data reported. The information on the participants is confidential and safe-guarded against unauthorised individuals.

Even though these ethical issues were considered, it is important to remember that all ethical issues cannot be settled before the research has started and the researcher was open to new dilemmas that may arise during the research process (Kvale & Brinkmann, 2009:69).

The above includes the ethical principles of justice, non-maleficence, beneficence and autonomy. This study has been ethical approved by the North-West University (NWU-00030-12-S1) and the Student Research Ethics Committee of the University of Pretoria (S155/2012) (refer to ADDENDUM 2-3).

2.6 CONCLUSION

Chapter two discussed the mixed method approach utilised in this study. The integrative literature review and interviews were both discussed according to its processes and rigour. The chapter was concluded with the ethical values considered by the researcher for this study. The realisation of the integrative literature review as the first phase of this study will be discussed in chapter three.

Chapter 3: Realisation of the integrative literature review

3.1 INTRODUCTION TO THE CHAPTER

The integrative literature review was the first phase of this mixed method study and addressed the first objective of the study (refer to Figure 3-1). The integrative literature review is a systematic process aiming to summarise and synthesise the results of high methodological studies and reach a conclusion on the support needs of parents of infants with complex health needs.

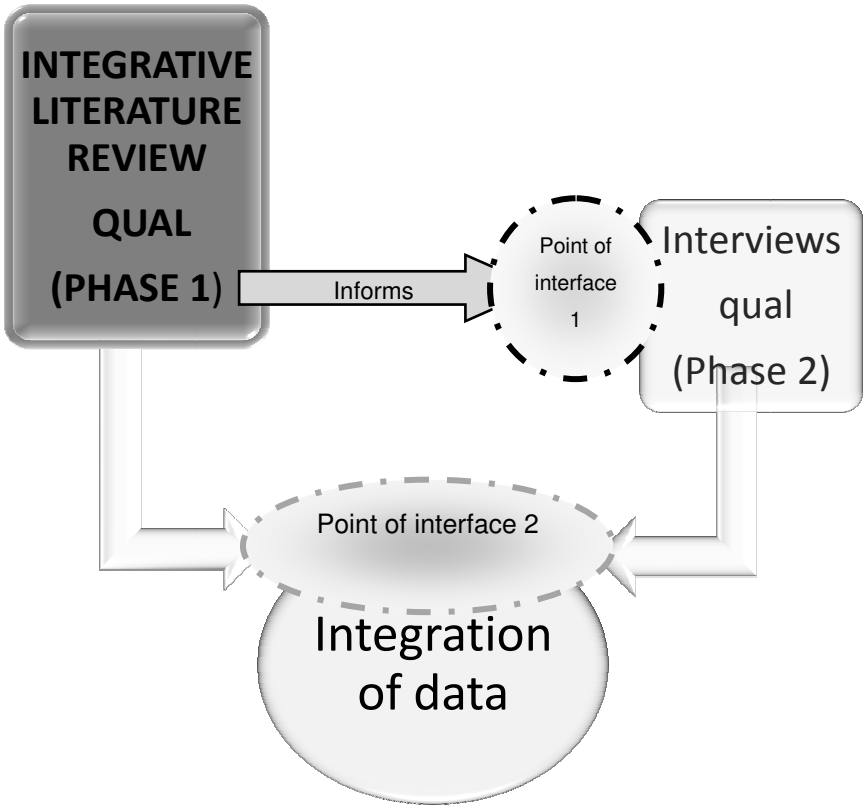

Figure 3-1: Phase 1 - integrative literature review

3.2 STEPS OF THE INTEGRATIVE LITERATURE REVIEW

The review question, realisation of the search, critical appraisal, data analysis and synthesis and concluding statements will be discussed in this chapter as the steps of the integrative literature review.

3.2.1 THE REVIEW QUESTION

The following review question was formulated using the variables identified through applying the PICOT format (refer to paragraph 2.4.2.1): *What are the support needs of parents in the community with infants with complex health needs that are under the age of one year?* Table 2-2 indicates the variables of the review question identified using the PICOT format. The following multi-stage search was executed to address this question.

3.2.2 REALISATION OF THE SEARCH

Data was collected using a multi-stage search. Exclusion and inclusion criteria were used to direct the search process and selection of relevant studies. An audit trail of the search process was kept. This included good record keeping of the databases used, the date of search and key words used, as well as the studies to be included for critical appraisal.

A multi-stage, purposive search was done in stages using six data sources summarised below. When an article was included during a stage, it was excluded in the next stages.

3.2.2.1 Data source 1: Electronic databases via search platforms

An electronic database is a structured and organised data source that is accessible electronically, meaning that a computer program assists the user in searching and selecting the desired data. A platform is a framework through which different electronic databases can be accessed simultaneously.

The platforms used in this data source were EBSCOhost and Scopus. EBSCOhost provides information resources from thousands of institutions worldwide and Scopus provides peer-reviewed literature and is the world's largest providing database on abstracts and citations of this kind.

EBSCOhost was searched with the following as chosen electronic databases: Academic Search Premier, Africa-Wide Information, CINAHL with Full Text, ERIC, Health Source – Consumer Edition, Health Source: Nursing/Academic Edition, MasterFILE Premier, MEDLINE, PsycARTICLES, PsychINFO and SocINDEX with Full Text.

The databases are described as found on EBSCOhost.

Academic Search Premier: A multi-disciplinary database providing full text for more than 4600 journals, which also includes about 3900 peer-reviewed titles.

Africa-Wide Information: An essential database on African research and information, offering a unique coverage on all facets of Africa and African studies.

CINAHL with Full Text: The most comprehensive source of full text for nursing and allied health journals, dating back to 1981.

ERIC (Education Resource Information Centre): This database contains a million records, linking to thousands of full-text articles, dating back to 1966.

Health Source – Consumer Edition: This database is a collection of consumer health information, including many health topics, accessing nearly 80 full text consumer health magazines.

Health source: Nursing/Academic Edition: This database provides scholarly full text journals that focus on many medical disciplines.

MasterFILE Premier: A multidisciplinary database covering a large area of subjects, dating back to 1975. This database is updated daily via EBSCOhost.

MEDLINE: A database providing authoritative multidisciplinary medical information from current biomedical journals.

PsycARTICLES: This database is a source of full text, peer-reviewed, scholarly and scientific articles in psychology.

PsycINFO: This database is the largest source of peer-reviewed literature in behavioural science and mental health, dating back to the 1800's.

SocINDEX with Full Text: This is a sociology research database. It includes full text for journals, books, monographs and conference papers.

The following key words were used to search EBSCOhost: parent* need* AND infant* OR bab* AND support OR special OR complex health OR fragile OR disab* OR medical*. The search was limited by date from 1986 to present. 506 articles were found (400 after duplicates were removed). From these nine articles were included for critical appraisal (N=9).

For Scopus the key words parent* need* AND bab* OR infant* AND special OR complex health OR fragile OR disab* OR medical* were used in the 'title/abstract or key words' section. The search was limited by date from 1986 to present. 681 articles were found with this search of which eight articles met the inclusion criteria. Two articles were duplicates from the search in EBSCOhost and six were included for critical appraisal (N=6).

15 articles from this sample were included for critical appraisal (n=15) and the search results are available in ADDENDUM 3-1.

3.2.2.2 Data source 2: Databases via the catalogue not included in the platforms of stage one

These are electronic databases not included in the previous sample. They were chosen from the catalogue for databases. The databases for this sample were Cochrane library, Proquest, SAGE journals online and ScienceDirect Journals. Databases are described as found on the catalogue.

Cochrane library: This is a collection of databases containing high-quality, independent evidence on health care related topics.

Proquest: This is the most comprehensive database on dissertations and theses in the world.

SAGE journals online: This database provides access to the full text of individual SAGE journals and includes topics on business, humanities, social science, science, medicine and technology.

ScienceDirect journals: This is a full text scientific database providing articles on peer-reviewed journals and chapters from books.

In Cochrane library the key words parent* need* AND bab* OR infant* AND support OR special OR complex health OR fragile OR disab* OR medical* were used in the 'title/abstract or key words' section. 30 articles were found with this search and none met the inclusion criteria to be included for critical appraisal (N=0).

Proquest was searched with the key words parent* need* AND bab* OR infant* AND special OR complex health OR fragile OR disab* OR medical* in the abstract section of dissertations and theses. The search was limited to the date 1986 to present and 146 dissertations and theses were found. Three of these met the inclusion criteria, but only two were included for critical appraisal as one was a duplicate from the search in EBSCOhost (N=2).

In SAGE journals online the key words parent* need* were used in the abstract, limited from the date January 1986. Any use of more key words delivered no search results. With this search 22 articles were found of which none was included for critical appraisal as none of the articles met the inclusion criteria (N=0).

In ScienceDirect journals the key words parent* need* AND bab* OR infant* AND support OR special OR complex health OR fragile OR disab* OR medical* were used in the 'title, abstract or key word' section. The search was limited from 1986 to present, in subjects medicine and dentistry, nursing and health professions and psychology. The search found 83 articles and none were included for critical appraisal as none of the articles met the inclusion criteria (N=0).

A total number of two articles were included from this data source for critical appraisal (n=2) and the search results are available in ADDENDUM 3-1.

3.2.2.3 Data source 3: Journals via the alphabetical journal list not included in the first two stages

This sample searched all printed electronic journals not available electronically from the first two stages. First the link on the library webpage navigating the user to the alphabetical list of journals was chosen. On this page, under the heading subjects, medicine were chosen and then nursing. Nursing showed 313 journals available. All journals also available via EBSCOhost and ScienceDirect were excluded as they were already searched. Four journals with applicable titles were then identified to be searched.

In *Cancer Nursing – Ovid* the link to 'Ovid Nursing full text plus' was chosen. The key words parent* need AND infant were searched in all issues and delivered 14 hits. None met the inclusion criteria (N=0).

In *MCN The American journal of maternal and child nursing* the link to 'journals@ovid' was chosen. The key words parent* need AND infant were searched in all issues and delivered 79 hits. None of these articles met the inclusion criteria and were included for critical appraisal (N=0).

In *N and HC: Perspectives on community* the link 'Ovid nursing collection one' was selected. The key words parent* need AND infant were used in all issues and this resulted in no hits (N=0).

In *Nursing Research* the link 'journals@ovid' was selected. The key words parent* need AND infant were used to search all issues and delivered 73 hits. None of these articles met the inclusion criteria and were included for critical appraisal (N=0).

Next, under the medicine subject heading, paediatrics was also chosen and then the subject Child health – child health services. Seven journals were available in this subject, all accessible via EBSCOhost or ScienceDirect and therefore not searched again.

From this data source no articles were included for critical appraisal (n=0) and the search results are available in ADDENDUM 3-1.

3.2.2.4 Data source 4: Pubmed and Google Scholar

In Google Scholar 'Advanced Scholar Search' was selected. Key words were searched in the subject areas of 'biology, life sciences and environmental science' limited from 1986 to 2011. A large combination of key words delivered a hit of over 16000 articles and therefore the key words were searched in separate searches to ensure relevancy of the search. The key words 'parent need' was searched in the title (all words to be included) and delivered eight hits of

which none met the inclusion criteria. Then 'special needs' was searched in the same way (excluding citations) and delivered 274 hits of which none met the inclusion criteria. 'Infants' was also searched in the same fashion and delivered 239 hits of which none met the inclusion criteria (N=0).

In Pubmed the 'Advanced Search' was selected and the key words used were parent* needs (somewhere in the title) AND infant OR bab* AND support OR complex health (in title or abstract). Limiters added were to humans, clinical trial, meta-analysis, practice guideline, randomized controlled trial, review, case reports, clinical conference, comparative study, controlled clinical trial, guideline, interview, journal article, all Infant: birth-23 months and publication date from 1986/01/01 to 2011/10/31. This delivered 23 hits of which one article was a duplicate from the EBSCOhost search. No other articles were relevant to be included for critical appraisal (N=0).

From the fourth data source no articles were included for critical appraisal (n=0) and the search results are available in ADDENDUM 3-1.

3.2.2.5 Data source 5: Manual search of the reference lists of the articles included for critical appraisal

In data source five the reference list of all relevant articles included for critical appraisal from the previous data sources were searched. 744 titles and abstracts were scanned for relevance. Five articles were identified, of which one was a critical literature review (Fisher, 2001). From this review the original articles reviewed were read to see if it met the inclusion criteria of this study. One article did meet the inclusion criteria and was included for critical appraisal. From this data source five articles were critically appraised (n=5) and the search results are available in ADDENDUM 3-1.

3.2.2.6 Data source 6: Personal contact with prominent published researchers in the field via e-mail

The studies included for critical appraisal were examined and one author was identified as a prominent published researcher in the field. This was done by examining the studies included for referencing to certain authors and publications on the subject matter of parents of infants with complex health needs. Dr. Susan Kirk was contacted per e-mail and asked to share all her relevant articles related to the topic. She sent a list of all her published articles, a total of ten, and no non-published data. This list was compared to the findings of the multi-stage done on the previous five data sources. Two articles were identified that met the inclusion criteria. These articles reported the same study as one of the articles already included for critical appraisal, but with a different emphasis. As the article already included reported the same findings as these

two articles and with a greater emphasis on parental support needs, these two articles were not included for critical appraisal. From this data source nil articles were included for critical appraisal (n=0) and the list of articles published by Kirk is available in ADDENDUM 3-1.

From the multi-stage search 22 studies were included for critical appraisal (n=22).

3.2.2.7 A summary of the realisation of the results of the search

Six data sources were searched with preselected key words. All documents from every data source were scanned for inclusion and exclusion criteria. Articles already included from a preceding data source were not included again. When the researcher could not include or exclude an article by reading the title and abstract, she read the full text article and reasons for excluding articles after reading the full text are provided in Table 3-1. This section is included here for visual demonstration on how the process unfolded. The complete set of data is included in ADDENDUM 3-1.

Table 3-1: Reasons for excluding full text articles read

Article title	Reason for exclusion
Data source 1: Electronic databases via search platforms	
Baack, C.J. 2006. Maternal stress and coping when a child is fed enterally. Ohio: The Ohio State University. (Diss. – PhD.)	Does not report on parental needs
Fitzpatrick, E. 2007. Population infant hearing screening to intervention: determinants of outcome from the parents' perspectives. Ottawa: University of Ottawa. (Thesis – PhD.)	Does not report on parental needs
Franklin, L. & Rodger, S. 2003. Parents' perpective on feeding medically compromised children: implications for occupational therapy. *Australian occupational therapy journal,* 50(3):137-147.	Not infants (16 months to 6 years)
Hall, S. 1996. An exploration of parental perception of the nature and level of support needed to care for their children with special needs. *Journal of advanced nursing,* 24(3):512-521.	Does not report on parental needs
Hanlin, M.F. & Deppe, J. 1990. Discharging the premature infant: family issues and implications for intervention. *Topics in early childhood special education,* 9(4):15-25.	Does not report on parental needs
Lynch, M. 1990. Home care of the ventilator-dependent child. *CHC,* 19(3):169-173.	Does not report on parental needs
Lynn, D.R. 2002. Parenting and childhood chronicity: making visible the invisible work. *Journal of pediatric nursing,* 17(6):424-438.	Not infants (15 months – 16 years)
Russ, S.A., Kuo, A.A., Poulakis, Z., Barker, M., Rickards, F., Saunders, K., Jarman, F.C., Wake, M. & Oberklaid, F. 2004. Qualitative analysis of parents' experience with early detection of hearing loss. *Archives of disease in childhood,* 89(4):353-358.	Does not report on parental needs
Zaidman-Zait, A. & Jameson, J.R. 2007. Providing web-based support for families of infants and young children with established disabilities. *Infants and young children,* 20(1):11-25.	Does not report on parental needs
Yucel, E., Derim, D. & Celik, D. 2008. The needs of hearing impaired children's parents who attend to auditory verbal therapy-counseling program. *International journal of pediatric otorhinolaryngology,* 72(7):1097-1111.	Not infants (24-238 months)

Article title	Reason for exclusion
Data source 2: Databases via the catalogue not included in the platforms of stage one	
Ammerman, S.B. 2009. The impact of hearing loss on mother-infant bonding. The university of Arizona. (Diss. – PhD.)	Does not report on parental needs
Johnston, B.D., Huebner, C.E., Tyll, L.T., Barlow, W.E. & Thompson, R.S. 2004. Expanding developmental and behavioural services for newborns in primary care. *American journal of preventative medicine,* 26(4):356-366.	Does not report on parental needs
Kerr, L.M.J., Harrison, M.B., Medves, J., Tranmer, J.E. & Fitch, M.I. 2007. Understanding the supportive care needs of parents of children with cancer: an approach to local needs assessment. *Journal of pediatric oncology nursing,* 24(5):279-293	Not infants (mostly 13 – 18 years)
McIntosh, J. & Runciman, P. 2006. Exploring the role of partnership in the home care of children with special health needs: qualitative findings from two service evaluations. *International journal of nursing studies,* 45(5):714-726.	Does not report on parental needs
Nicolaou, M. & Glazebrook, C. 2008. Emotional support for families of sick neonates. *Pediatrics and child health,* 18(4):196-199.	Infants in NICU
Data source 3: Journals via the alphabetical journal list not included in the first two stages	
Bakewell-Sachs, S. & Gennaro, S. 2004. Parenting the post-NICU premature infant. *Maternal child nursing,* 29(6):398-403.	Does not report on parental needs
Keefe, M.R. Barbosa, G.A. & Froese-Fretz, A. 2005. An intervention program for families with irritable infants. *Maternal child nursing,* 30(4):230-236.	Does not report on parental needs
Martinson, I., Liu-Chiang, C. & Yi-Hua, L. 1997. Distress symptoms and support systems of Chinese parents of children with cancer. *Cancer nursing,* 20(2):94-99.	Does not report on parental needs
Norberg, A.L. & Boman, K.K. 2007. Parents' perception of support when a child has cancer: a longitudinal perspective. *Cancer nursing*, 30(4):294-301.	Does not report on parental needs and children's age not specified
Ritchie, S.K. 2000. Primary care of the premature infant discharged from the neonatal intensive care unit. *Maternal child nursing,* 27(2):76-85.	Does not report on parental needs
Swartz, M.K. 2005. Parenting preterm infants: a meta-synthesis. *Maternal child nursing,* 30(2):115-120.	Does not report on parental needs

Only articles that met the inclusion criteria were critically appraised. Figure 3-2 provides a summary of the multi-stage search.

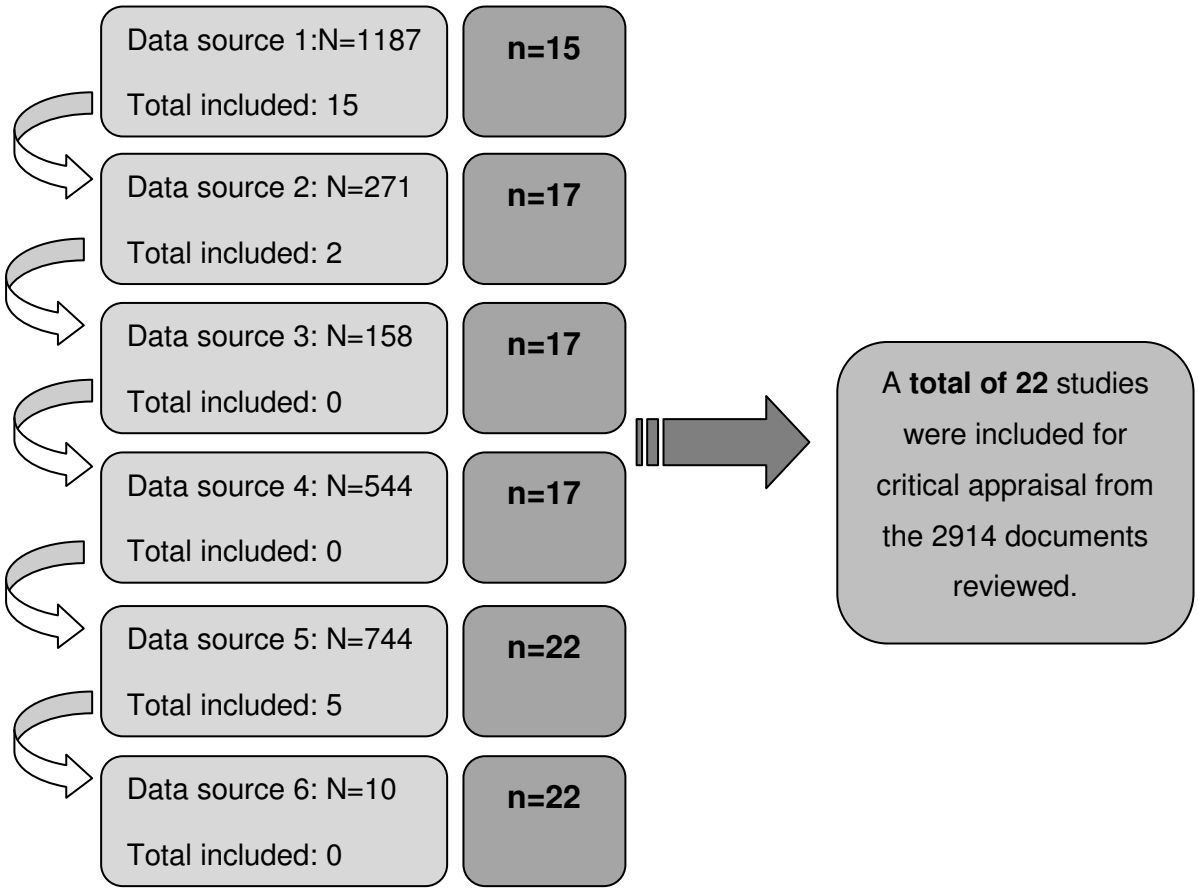

Figure 3-2: A summary of the realization of the search

3.2.3 CRITICAL APPRAISAL

During this step the relevant studies found in the search were critically appraised. The aim of critical appraisal was to systematically evaluate the methodological quality of the studies that complied with the inclusion criteria. The appraised articles were then also graded (refer to paragraph 2.4.2.3) according to its strength of evidence and relevancy to the research question. The strength of evidence can be graded as follows (ADA, 2010:88):

Grade I: Good – the study has a strong design for answering the addressed research question and is free of flaws in design, bias and doubts about generalisability. Sufficient sample sizes have been utilised.
Grade II: Fair – the study has a strong design for answering the addressed research question, but has flaws in design, do not address bias and there are doubts about generalisability and adequate sample size.

Grade III: Limited – the study has a weak design for answering the addressed research question. The study has inadequate sample size, flaws in design, bias and lacks generalisability.

3.2.3.1 Role of the independent reviewer

The independent reviewer took part in the selection and appraisal of the studies. She was provided with the appraisal instruments for quantitative and qualitative studies and her written feedback was received on each study appraised. The researcher and independent reviewer differed on three studies appraised with regard to the methodology of one study and the quality of methodology of the other two studies. After a telephonic discussion consensus was reached on these studies.

Using specified instruments for critical appraisal facilitated consensus discussions on the grading of the studies as two reviewers appraised the documents with the same instruments independently. It also established a replicable review since another reviewer can use the same instrument to replicate the review and consider the findings.

3.2.3.2 Appraisal results

Table 3-2 summarises the results of the critical appraisal. It provides the studies included and excluded due to quality after appraisal, the tools used for appraisal with each study and the grading of each study. The ratings are the scores allocated through critical appraisal of the studies with the specific critical appraisal instruments discussed in paragraph 2.4.2.3. A higher rating indicates a higher methodological quality of the study. The correlation between the rating of the researcher and independent reviewer showed a strong correlation (0.94), using Pearson's correlation coefficient. A t-test was also done on the pared data and no difference in average was found between the rating of the researcher and independent reviewer.

Table 3-2: Critical appraisal results

Author	Tool used for critical appraisal	Researcher rating	Independent reviewer rating	Grading	Included	Excluded
From data source 1: Electronic databases via search platforms						
Aytch *et al.*, 2001	Critical review form – qualitative studies (Letts *et al.*, 2007)	**11.5**	**11**	**I**	√	
Eaves *et al.*, 1996	Checklist for assessing quality of quantitative studies (Kmet *et al.*, 2004:4)	4	4.5	III		√
Hummelinck & Pollock, 2005	Critical review form – qualitative studies (Letts *et al.*, 2007)	3	3	III		√
Kerr & McIntosh, 2000	Critical review form – qualitative studies (Letts *et al.*, 2007)	**7**	**7.5**	**II**	√	
Kirk & Glendinning, 2002	Critical review form – qualitative studies (Letts *et al.*, 2007)	**7**	**7**	**II**	√	
Konrad, 2007	Critical review form – qualitative studies (Letts *et al.*, 2007)	**8**	**7**	**II**	√	
McPhee, 2010	Checklist for assessing quality of quantitative studies (Kmet *et al.*, 2004:4)	**8.5**	**8**	**II**	√	
Moola, 1996	Checklist for assessing quality of quantitative studies (Kmet *et al.*, 2004:4)	**7.5**	**6**	**II**	√	
Molinari & Freeborn, 2006	Critical review form – qualitative studies (Letts *et al.*, 2007)	**8**	**8.5**	**II**	√	
Muggli *et al.*, 2009	Critical review form – qualitative studies (Letts *et al.*, 2007)	**8**	**8.5**	**II**	√	
Olsen & Maslin-Prothero, 2001	Critical review form – qualitative studies (Letts *et al.*, 2007)	7	6.5	III		√
Reilly & Platz, 2004	Checklist for assessing quality of quantitative studies (Kmet *et al.*, 2004:4)	6	6	III		√
Sontag & Schacht, 1994	Checklist for assessing quality of quantitative studies (Kmet *et al.*, 2004:4)	5	5	III		√
Tong *et al.*, 2009	Critical review form – qualitative studies (Letts *et al.*, 2007)	**9**	**9**	**I**	√	

Author	Tool used for critical appraisal	Researcher rating	Independent reviewer rating	Grading	Included	Excluded
Young *et al*., 1988	Critical review form – qualitative studies (Letts *et al*., 2007)	**7.5**	**8**	**II**	√	
From data source 2: Databases via the catalogue not included in the platforms of stage one						
Hirano, 2011	Critical review form – qualitative studies (Letts *et al*., 2007)	3	2	III		√
Newton, 2006	Checklist for assessing quality of quantitative studies (Kmet *et al*., 2004:4)	**7**	**7**	**II**	√	
From data source 5: Manual search of the reference lists of the articles included for critical appraisal						
Bailey *et al*., 1992	Checklist for assessing quality of quantitative studies (Kmet *et al*., 2004:4)	**8**	**8.5**	**II**	√	
Bailey &Simeonsson, 1988	Critical review form – qualitative studies (Letts *et al*., 2007	3	4.5	III		√
Diehl *et al*., 1991	Critical review form – qualitative studies (Letts *et al*., 2007)	**7.5**	**6.5**	**II**	√	
Pelchat *et al*., 2004	Checklist for assessing quality of quantitative studies (Kmet *et al*., 2004:4	**8**	**7**	**II**	√	
Redmond & Richardson, 2003	Critical review form – qualitative studies (Letts *et al*., 2007)	5	6.5	III		√

Critical appraisal was the third step in the integrative literature review. Fourteen articles were found to be of good quality (grade I and II studies) and were used in data analysis and synthesis.

3.2.4 DATA ANALYSIS AND SYNTHESIS WITH CONCLUDING STATEMENTS

After the critical appraisal was done and consensus reached on the studies to be included, data analysis and synthesis were done on these studies. The primary sources were thematically analysed relating to the support needs of parents of infants with complex health needs. The review question guided the integrative literature in all stages of the review, also in data analysis. The aim of thematic analysis was to directly reflect the main ideas of the included research studies and not to develop new explanations of the findings.

Thematic analysis can organise and summarise findings from diverse research studies of both qualitative and quantitative nature (Pope *et al.*, 2007:96), making it the ideal approach for the integrative literature review. This method of analysis is flexible and can be used within different theoretical frameworks (Braun & Clarke, 2006:78,81). In this study the support needs of parents of infants with complex health needs were identified as themes through the integrative literature review in order to know the worldview of these parents within the theoretical framework of modelling and role-modelling (Erickson *et al.*, 1983).

A stepwise process, as explained by Creswell (2009:184-189), was used to analyse the data. The *first step* was to organise and prepare the data. Data extraction of each study was done according to author, year of publication, study design, aim of the study, population and sample, summary of the findings relating to the needs of parent of infants with complex health needs, conclusion and limitations of each study (refer to ADDENDUM 3-2). It was too complex to develop themes from the data extracted, thus even though data extraction organised the data, analysis itself was done directly from the findings of each article. This also increased the rigour of the study by ensuring that analysis was not done on the interpretation of data, but on the original data. Data extraction prepared the reviewers for analysis by identifying the findings related to the support needs of parents of infants with complex health needs in the included studies.

During the *second step* the findings of the studies were actively read and re-read. Patterns of meaning were identified and therefore a sense of the embedded data was acquired. Notes were made on possible ideas for categories and themes.

The *third step* involved coding of the data and data were therefore organised into meaningful groups, which represented a basic segment of data (Braun & Clarke, 2006:88). Coding was done manually, using highlighters to colour segments of the text relating to each other. An example of how codes were applied can be seen in Figure 3-3. An independent reviewer was involved in coding of the data and consensus was reached on the categorising of data.

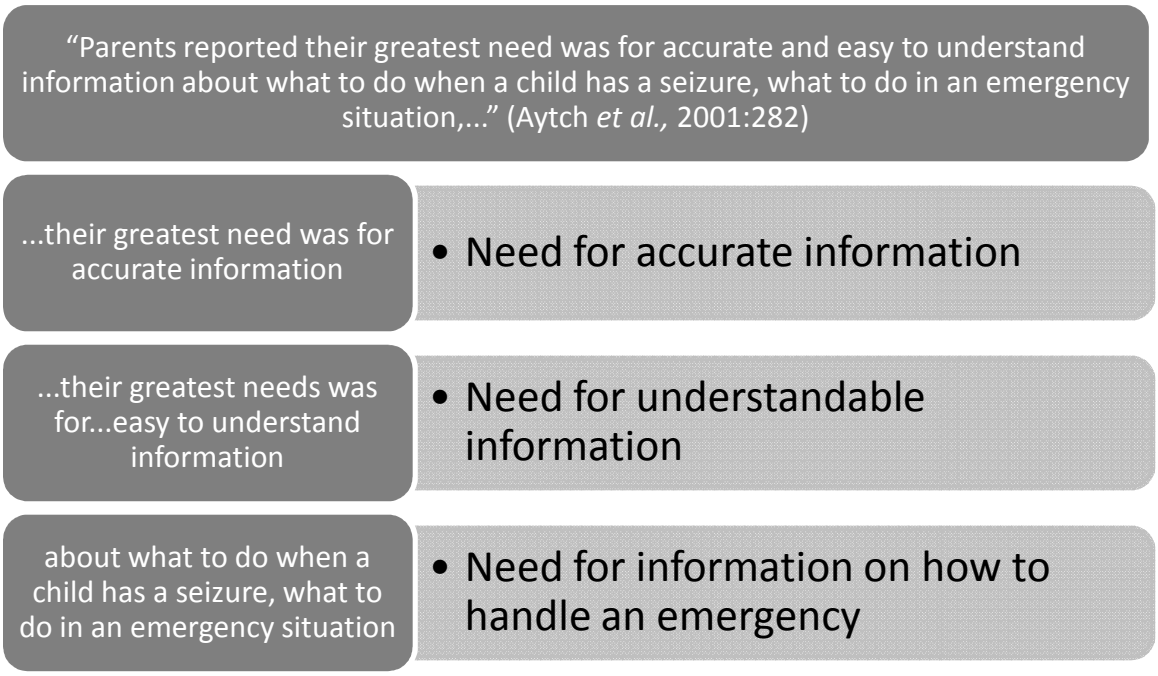

Figure 3-3: Example of how codes were applied to data during analysis

Codes that formed a pattern were highlighted with the same colour on the text. Notes in pencil were also made on the text regarding the patterns. Next, the codes identified were organised into possible broader themes. The themes were then revised. At this stage some of the themes were collapsed into one theme with sub-themes rather than two separate main themes. Simple themes on the support needs of parents of infants with complex health needs were developed and categorised according to similar topics. These themes were supported by the text and initial definitions for each theme were developed. After development of the themes the text was read again, taking each theme and examining the data for related information to that theme. This is called axial coding. Finally the themes were named, defined and supported with data.

A theme should capture something important related to the research question (Braun & Clarke, 2006:82). Themes therefore did not emerge from the data set by itself, but were actively influenced by the researcher through her identification and selection of patterns (Braun & Clarke, 2006:80) on what she thought was related to the research question. A theme was identified only according to its relevance to the research question and could appear anywhere in the findings of the studies. It was not influenced by how often it appeared in the data set or how much attention was given to it in different data items. Themes were therefore identified if they related to the support needs of parents of infants with complex health needs.

During step two and three the steps for organising qualitative data described by Tesch (1990:142-145) were also applied. These steps involved getting a sense of the whole by

reading and re-reading the data and then identifying topics in the data. Topics from the different studies were then compared and grouped together if similar, without excluding topics that seemed unique and important to the research purpose. These preliminary topics were then applied to the data not yet used for analysis. This process refined the topics and identified new topics. The topics were then categorised and relationships between the topics were identified. These categories of topics were described as themes and the content of each theme were identified.

During *step four* each theme was discussed separately, although in relation to other themes. Although no preset themes were identified for analysis, the researcher still approached the data with a specific research question and coded the data with this question in mind. Data in the studies not related to the research question were ignored. This means a theoretical (or deductive) thematic analysis was followed (Braun & Clarke, 2006:84).

The main themes identified were: need for information, need for parent-to-parent support, need for professional support, need for self-confidence in the care of the infant and need for social support (refer to Figure 3-4). *Steps five and six* in the analysis process presented and interpreted the data by discussing each main theme separately and concluding the themes with concluding statements.

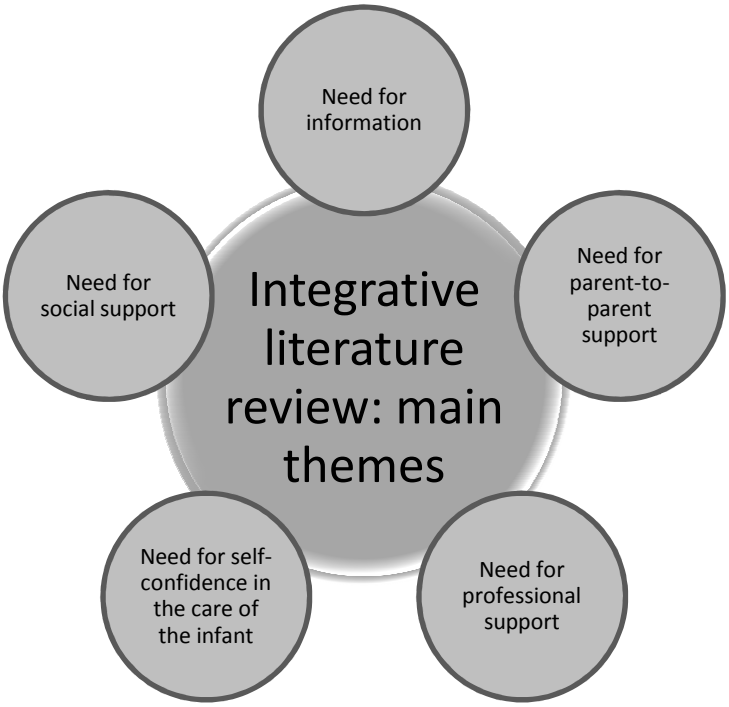

Figure 3-4: The main themes of the integrative literature review

3.2.4.1 Need for information

The need for information was a major theme emerging from every study analysed. In Table 3-3 the outline of analysis of this theme is provided. The need for information theme is divided into two sub-themes relating to what information parents need and how they want to receive this information.

Table 3-3: Need for information - outline of analysis

Main theme: Need for information		
This theme relates to the topics and kind of information needed by parents. It includes educational, practical and prospective information.		
Supporting literature	**Sub-themes**	**Themes**
Need for information on the child's disease and the effect on the child's development and learning Grade I: Aytch *et al*., 2001:282; Tong *et al*., 2010:555 Grade II: Bailey *et al.,* 1992:5; Diehl *et al*., 1991:173,177; Kerr & McIntosh, 2000:314; Kirk & Glendinning, 2002:632; McPhee, 2010:80; Molinari & Freeborn, 2006:32; Moola, 1996:132,183; Newton, 2006:40; Pelchat *et al*., 2004:134; Young *et al*., 1988:189 **Need for information on what to do in a emergency situation** Grade I: Aytch *et al*., 2001:282 Grade II: Young *et al*., 1988:189 **Need for information on the effects, side-effects and interaction of medication** Grade I: Aytch *et al*., 2001:282 Grade II: Diehl *et al*., 1991:176 **Need for more information on the risks and benefits of procedures performed on their children** Grade I: Tong *et al*., 2010:555 Grade II: Diehl *et al*., 1991:176	Need for educational information	Types of information needed
Need for information on behavioural issues of the child Grade I: Tong *et al.,* 2010:553 Grade II: Molinari & Freeborn, 2006:33; Newton, 2006:40 **Need for information on equipment available and how to access it** Grade II: Diehl *et al*., 1991:174 **Need for information on home care** Grade II: Diehl *et al*., 1991:173 **Need for information on daily caregiving like nutrition, bathing and transporting of the child** Grade I: Tong *et al*., 2010:553 Grade II: Diehl *et al*., 1991:173 **Need for information on coping strategies and parenting** Grade II: Molinari & Freeborn, 2006:32	Need for practical information and advice	

Main theme: Need for information		
This theme relates to the topics and kind of information needed by parents. It includes educational, practical and prospective information.		
Supporting literature	**Sub-themes**	**Themes**
Need for information on community resources and support available Grade I: Aytch *et al*., 2001:282; Tong *et al*., 2010:555 Grade II: Bailey *et al*., 1992:5; Diehl *et al*., 1991:173; Kirk & Glendinning, 2002:632; Molinari & Freeborn, 2006:32; Moola, 1996:139; Pelchat *et al*., 2004:134	Need for information on available resources	Types of information needed
Need for information on what the future holds Grade II: Bailey *et al.,* 1992:5; Diehl *et al*., 1991:173; Kerr & McIntosh, 2000:315; Moola, 1996:142 **Need to be informed on the changing needs of the child** Grade II: Diehl *et al*., 1991:177	Need for information on the future	
Need for accurate and understandable information Grade I: Aytch *et al*., 2001:282 Grade II: Diehl *et al*.,1991:173,176; Pelchat *et al*., 2004:134 **Need for updated, relevant and enough information** Grade II: Diehl *et al*., 1991:173; Kirk & Glendinning, 2002:632; Muggli *et al*., 2009:59	Need for accurate, relevant information	Communication
Need for written and visual educational material Grade I: Aytch *et al*., 2001:282; Tong *et al*., 2010:555 Grade II: Bailey *et al*., 1992:5; Pelchat *et al*., 2004:137 **Need for educational material to share with care givers of child** Grade I: Aytch *et al*., 2001:282	Need for written information	
Prefer information to be provided at an early stage Grade II: Muggli *et al*., 2009:59; Pelchat *et al*., 2004:134 **Need for information to be given on the right time** Grade II: Diehl *et al*., 1991:173	Need for information at the right time	

Main theme: Need for information		
This theme relates to the topics and kind of information needed by parents. It includes educational, practical and prospective information.		
Supporting literature	**Sub-themes**	**Themes**
Prefer to receive information from a knowledgeable professional Grade II: Moola, 1996:140	Source of information	Communication
Using the internet as source of information Grade I: Aytch *et al*., 2001:282; Tong *et al*., 2010:555 Grade II: Muggli *et al*., 2009:59		
Internet as source of information can be overwhelming Grade I: Aytch *et al*., 2001:282 Grade II: Muggli *et al*., 2009:59		

a. Types of information needed

This sub-theme relates to different types of information parents need, including educational information and practical advice.

The need for information on various topics has been frequently described in the included studies, especially the need for information on the condition of the child (Aytch *et al.*, 2001:282; Bailey *et al.*, 1992:5; Diehl *et al.*, 1991:173,177; Kerr & McIntosh, 2000:314; Kirk & Glendinning, 2002:632; McPhee, 2010:80; Molinari & Freeborn, 2006:32; Moola, 1996:132,183; Newton, 2006:40; Pelchat *et al.*, 2004:134; Tong *et al.*, 2010:555; Young *et al.*, 1988:189). This related to the need parents have for education on all aspects of their infant's care, including information on medication use and administration, equipment available and how to handle an emergency situation (Aytch *et al.*, 2001:282; Diehl *et al.*, 1991:173&176; Young *et al.*, 1988:189).

The second need identified was the need for practical advice and information. This included daily care giving activities like how and what to feed the child, bathing, how to transport the child and how to manage daily schedules (Diehl *et al.*, 1991:177; Tong *et al.*, 2010:553). Information on this creates confidence in the parents' ability to care for their infant and satisfy the need for self-confidence in the care of their infant as discussed in paragraph 3.2.4.4.

A third type of information emphasised in many of the studies was the need for information on services, resources and support available (Aytch *et al.*, 2001:282; Bailey *et al.*, 1992:5; Diehl *et al.*, 1991:173; Kirk & Glendinning, 2002:632; Molinari & Freeborn, 2006:32; Moola, 1996:139; Pelchat *et al.*, 2004:134; Tong *et al.*, 2010:555) and how to access them.

A fourth need identified was the need for parents to know what to expect from the future (Bailey *et al.,* 1992:5; Diehl *et al.*, 1991:173; Kerr & McIntosh, 2000:315; Moola, 1996:142). Molinari and Freeborn (2006:33), Newton (2006:40) and Tong *et al.* (2010:553) reported that parents need more information on behavioural issues in their children with complex health needs. Although this is not related to infants, it is important information for the future.

A fifth type of information needed by parents was information on the development of their child and how it is influenced by the child's condition (Aytch *et al.*, 2001: 282; Diehl *et al.*, 1991:177). Not only is the type of information needed by parents important, but also the way it is communicated. This sub-theme is concluded by two statements.

Concluding statement 1: Parents need information regarding their infant's condition, care, daily routine, medication use, development and future.

Supporting literature: Aytch *et al.,* 2001:282; Bailey *et al.,* 1992:5; Diehl *et al.,* 1991:173,177; Kerr & McIntosh, 2000:314; Kirk & Glendinning, 2002:632, McPhee, 2010:80; Molinari & Freeborn, 2006:32; Moola, 1996:132,183; Newton, 2006:40; Pelchat *et al*., 2004:134; Tong *et al.,* 2010:555; Young *et al*., 1988:189

Concluding statement 2: Parents need information on services, resources and support available.

Supporting literature: Aytch *et al.,* 2001:282; Bailey *et al.,* 1992:5; Diehl *et al*., 1991:173; Kirk & Glendinning, 2002:632; Molinari & Freeborn, 2006:32; Moola, 1996:139; Pelchat *et al*., 2004:134; Tong *et al*., 2010:555

b. Communication

Communication of information relates to how parents want to receive information and when they want to receive information.

Although most parents reported receiving information, many said that the information was inadequate, irrelevant, too little, outdated and not given at the right time. It is apparent that parents have the need for updated, easy to understand, relevant and clear information (Aytch *et al*., 2001:282; Diehl *et al*., 1991:173; Kirk & Glendinning, 2002:632; Muggli *et al*., 2009:59; Kerr & McIntosh, 2000:314; Pelchat *et al*., 2004:134; Tong *et al*., 2010:553).

A second need identified was the need for written information (Aytch *et al*., 2001:282; Bailey *et al*., 1992:5; Pelchat *et al*., 2004:137; Tong *et al*., 2010:555). This is due to different reasons including to have written information available to share with family and friends and also care givers of the infant (Aytch *et al*., 2001:282; Bailey *et al*., 1992:5; Pelchat *et al*., 2004:137; Tong *et al*., 2010:555). This information is therefore to educate oneself and others on the condition and care of the child.

The participants in the study of Diehl *et al.* (1991:173) also reported that information should be given at the right time. Too much information given just after birth or diagnosis of the child is overwhelming and can be confusing. With this in mind, it is still important to provide information at an early stage (Muggli *et al*., 2009:59; Pelchat *et al*., 2004:134).

Participants in the study of Moola (1996:140) reported that they want to receive information from a knowledgeable professional, but it is important to reflect that parents use the Internet as a source of information (Aytch *et al*., 2001:282; Muggli *et al*., 2009:59; Tong *et al*., 2010:555). Some parents asked specifically for information to be made available online (Tong *et al*.,

2010:555). The need for information is universal and touches on every aspect of the infant's care and daily living of the parents. This sub-theme is concluded with three statements.

Concluding statement 3: Parents need written information on the care and condition of their infant and information to share with others.

Supporting literature: Aytch *et al.*, 2001:282; Bailey *et al.*, 1992:5; Pelchat *et al.*, 2004:137; Tong *et al.*, 2010:555

Concluding statement 4: Parents need accurate and up-to-date information they can understand.

Supporting literature: Aytch *et al.*, 2001:282; Diehl *et al.*, 1991:173,176; Kirk & Glendinning, 2002:632; Muggli *et al.*, 2009:59; Pelchat *et al.*, 2004:134

Concluding statement 5: Parents need information at an early stage from a health care professional.

Supporting literature: Moola, 1996:140; Muggli *et al.*, 2009:59; Pelchat *et al.*, 2004:134

3.2.4.2 Need for parent-to-parent support

This theme is supported by many of the articles (Aytch *et al.*, 2001, Kerr & McIntosh, 2000; Konrad, 2007; Moola, 1996; Muggli *et al.*, 2009; Tong *et al.*, 2010) and relates to parents' need to communicate and have contact with parents in a similar situation. The outline of the analysis for this theme is discussed in Table 3-4.

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Table 3-4: Need for parent-to-parent support theme - outline of analysis

Main theme: Need for parent-to-parent support		
This theme relates to the desire of parents to be in contact with other parents in a similar situation, to derive and give support to each other.		
Supporting literature	**Sub-theme**	**Theme**
Need to communicate with parents who share similar experiences Grade I: Aytch *et al*., 2001:282; Tong *et al*., 2010:555 Grade II: Bailey *et al*., 1992:5; Kerr & McIntosh, 2000:317; Konrad, 2007:121; Moola, 1996:143; Muggli *et al*., 2009:59	Need for parent-to-parent support groups	Need to communicate with other parents in the same situation.
Need for interaction with individual family with the same experience Grade I: Aytch *et al*., 2001:282 Grade II: Konrad, 2007:122; Kerr & McIntosh, 2000:316; Young *et al*., 1988:190		
Need for parent support groups Grade I: Aytch *et al*., 2001:282 Grade II: Diehl *et al*., 1991:173; Konrad, 2007:122; Kerr & McIntosh, 2000:316; Young *et al*., 1988:190		
Need for peer support to be organised Grade II: Muggli *et al*., 2009:59		
Need for offering support to other parents Grade II: Kerr & McIntosh, 2000:318	Contact with other parents are helpful	
Contact with other parents in similar situation is comforting Grade II: Konrad, 2007:121		
Information and resource sharing with other parents Grade II: Konrad, 2007:122		
Talking to other parents were helpful Grade I: Aytch *et al*., 2001:282		

Parents in similar situations have a perceived sameness that makes it easier to relate, share emotions and experiences and give support. Parents reported that they feel other parents in a similar situation are the only ones who truly understand how they feel (Kerr & McIntosh, 2000:317). Muggli *et al.* (2009:59) described parents as being desperate to speak to another family in the same situation, further emphasising the importance of having early access to other parents. Although some parents were hesitant to ask for support, they reported that they would have been grateful if it was offered to them (Muggli *et al.*, 2009:59). Mothers in the study done by Konrad (2007:121) strongly encouraged other parents to seek support from each other.

Contact with other parents creates awareness that they are not alone in this situation, and this provides comfort and reassurance (Kerr & McIntosh, 2000:317; Konrad, 2007:121). Support can be offered in the form of support groups or individual conversations.

Meeting parents that are in a similar situation does not only provide reassurance, but also gives new parents hope and a glimpse of the future. By seeing what parents have achieved and how other children are doing, satisfy partly the need to know what to expect from the future, which relates to the need for information theme discussed in paragraph 3.2.4.1.

Other reasons for seeking parent-to-parent support includes emotional support, information and resource sharing, validating experiences and to offer support (Kerr & McIntosh, 2000:317-318; Konrad, 2007:122). Parents do not just want to receive support, but also give it to others. Offering support has been described as an important part of the process of adaptation for these parents (Kerr & McIntosh, 2000:318) and mothers felt they had a lot to offer to other parents in terms of encouragement and information (Konrad, 2007: 123-124). This theme is concluded with two statements.

Concluding statement 6: Parents need to communicate, share experiences, emotions and information with parents in a similar situation.

Supporting literature: Aytch *et al.*, 2001:282; Bailey *et al.*, 1992:5; Diehl *et al.*, 1991:173; Kerr & McIntosh, 2000:317; Konrad, 2007:121; Moola, 1996:143; Muggli *et al.*, 2009:59; Tong *et al.*, 2010:555; Young *et al.*, 1988:190

Concluding statement 7: Parent-to-parent support is the receiving, as well as giving, of support.

Supporting literature: Kerr & McIntosh, 2000:318; Konrad, 2007:122

3.2.4.3 Need for professional support

The need for professional support was developed from many phrases identified in the studies and formed four themes. This main theme describes all needs related to professional services, including the type and quality of support needed from professionals. Each sub-theme will be discussed separately and the outline of the analysis is provided in Table 3-5.

Table 3-5: Need for professional support - outline of analysis

Main theme: Need for professional support		
This theme relates to all the aspects of what professional services parents need, including someone they can express their feelings to, one person to co-ordinate the care of the child and family, and the type and quality of support they need from professionals.		
Supporting literature	**Sub-theme**	**Theme**
Counselling from social workers were of limited usefulness Grade II: Muggli *et al.*, 2009:59 **Reluctant about genetic counselling and doubt the value of it** Grade II: Muggli *et al.*, 2009:60	Efficiency of counselling	Need for counselling
Need for someone to talk to, not directly related to the medical management of child Grade I: Aytch *et al.*, 2001:282 **Feelings of isolation and nobody to talk to** Grade II: Kerr & McIntosh, 2000:315 **Need for a familiar professional to talk to about worries and anxieties and discuss family problems** Grade II: Kirk & Glendinning, 2002:629; Molinari & Freeborn, 2006:32; Newton, 2006:40; Pelchat *et al.*, 2004:133 **Need for professionals to listen to parents** Grade II: Diehl *et al.*, 1991:174 **Expressing feelings and concerns allows for emotional support** Grade I: Tong *et al.*, 2011:553 Grade II: Kirk & Glendinning, 2002:629; Moola, 1996:152; Pelchat *et al.*, 2004:133	Personal need	
Need for help in responding to neighbours and friends Grade II: Newton, 2006:40 **Need to talk about death and dying of the child** Grade II: Diehl *et al.*, 1991:177	Topics of counselling	
Need for someone to guide them and link them to services Grade II: Muggli *et al.*, 2009:59 **Need for continuity of care and advice** Grade II: Muggli *et al.*, 2009:59 **Need for an approachable, available person to contact and seek advice from who is familiar with child's circumstances**	Need for a specific professional	Need for a service coordinator

Main theme: Need for professional support		
This theme relates to all the aspects of what professional services parents need, including someone they can express their feelings to, one person to co-ordinate the care of the child and family, and the type and quality of support they need from professionals.		
Supporting literature	**Sub-theme**	**Theme**
Grade II: Kirk & Glendinning, 2002:629 **Need for a professional to act as advocate for family** Grade II: Kirk & Glendinning, 2002:630	Need for a specific professional	Need for a service coordinator
Need for professional to organise services and act as liaison with other workers Grade II: Diehl *et al.*, 1991:173,174; Kirk & Glendinning, 2002:630; Molinari & Freeborn, 2006:31; Young *et al.*, 1988:189 **Need for someone to organise equipment and supplies** Grade II: Diehl *et al.*, 1991:173; Kirk & Glendinning, 2002:631; Young *et al.*, 1988:189	Need for someone to organise	
Need for access to knowledgeable people to discuss concerns and get advice from Grade I: Aytch *et al.*, 2001:282 Grade II: Kerr & McIntosh, 2000:316; Kirk & Glendinning, 2002:632 **Need for professional to provide hands-on care and give parents a break from caring** Grade II: Kirk & Glendinning, 2002:630-631 **Need for competent, knowledgeable, available professionals to provide quality care** Grade I: Tong *et al.*, 2010:551 Grade II: Diehl *et al.*, 1991:174; Molinari & Freeborn, 2006:31,33; Moola, 1996:144; Young *et al.*, 1988:190	Need for knowledgeable and available professionals	Need for accessible and approachable professionals
Need for honesty from professionals Grade I: Tong *et al.*, 2010:551 Grade II: Kirk & Glendinning, 2002:628 **Practical support from professionals are valued** Grade I: Kirk & Glendinning, 2002:630 **Willing professionals present at death, illness, tragedy and loss are a consolation** Grade II: Konrad, 2007:122	Value of professionals	

Main theme: Need for professional support		
This theme relates to all the aspects of what professional services parents need, including someone they can express their feelings to, one person to co-ordinate the care of the child and family, and the type and quality of support they need from professionals.		
Supporting literature	**Sub-theme**	**Theme**
Need for financial assistance Grade I: Tong *et al.*, 2010:554 Grade II: Bailey *et al.*, 1992:5; Diehl *et al.*, 1991:175; Molinari & Freeborn, 2006:32; Moola, 1996:135	Services for parents	Need for professional services
Need for family planning from a professional Grade II: Moola, 1996:153		
Child care and financial needs are more in mothers with infants than school aged children Grade II: Newton, 2006:39		
Early intervention services, services of support for parents, community resources, child care and financial services were not used by parents of premature infants, the first 6 months after discharge from NICU Grade I: McPhee, 2010:77		
Need for access to medical and developmental services Grade I: Aytch *et al.*, 2001:282	Services for infant	
Need for adequate and quality babysitting/child care/respite care Grade I: Aytch *et al.*, 2001:282 Grade II: Diehl *et al.*, 1991:172; McPhee, 2010:82; Young *et al.*, 1988:190		
Need for educational services for their children Grade II: Diehl *et al.*, 1991:175; Moola, 1996:134,140		
Need for quality health care for their children Grade I: Tong *et al.*, 2010:551 Grade II: McPhee, 2010:78; Molinari & Freeborn, 2006:30		

a. Need for counselling

This theme relates to parents' need for expressing their fears and anxieties while receiving positive input. From the analysed studies, it is apparent that many parents have the desire to talk to someone about their situation and express their feelings. They prefer talking to a professional who will be able to answer questions and lead them in the right direction, therefore offering them emotional support not found elsewhere (Kirk & Glendinning, 2002:629; Moola, 1996:152; Pelchat *et al.*, 2004:133; Tong *et al.*, 2010:553). Family members, although sympathetic, avoid talking about certain topics and are in many cases grieving themselves. Parents voiced that it can be difficult to communicate to other family members as they do not understand the situation and have many questions themselves (Newton, 2006:40; Tong *et al.*, 2010:555). Parents also want to discuss the sensitive topic of death and dying (Diehl *et al.*, 1991:177), which family members usually want to avoid.

Through counselling, parents come to better insight about their situation and they realise that they are not alone. Some parents expressed that the counsellor should not be directly involved in the child's medical care (Aytch *et al.*, 2001:282), but should be familiar with the family and their situation (Kirk & Glendinning, 2002:629; Molinari & Freeborn, 2006:32; Newton, 2006:40; Pelchat *et al.*, 2004:133). This enables the parents to speak freely, without having to explain their situation or omitting some of their concerns.

It is important to note that parents did report some form of counselling available, but that it was inefficient or of little value to them (Muggli *et al.*, 2009:59). This further emphasises that the correct information should be available to parents and that they need to have access to the correct professionals. This theme is concluded with one statement.

Concluding statement 8: Parents need to discuss their fears, anxieties and concerns with a familiar health care professional.

Supporting literature: Aytch *et al.*, 2001:282; Diehl *et al.*, 1991:177; Kirk & Glendinning, 2002:629; Molinari & Freeborn, 2006:32; Moola, 1996:152; Newton, 2006:40; Pelchat *et al.*, 2004:133

b. Need for a service coordinator

This theme relates to parents' need for one professional to supervise the care of their infant and that of the family. A service coordinator is a professional who assists the family in organising services and equipment, provides information and is familiar with the infant, the family and their care. A family should be specifically assigned to a service coordinator. This professional is also the link between all other professionals involved in the treatment of the infant.

The need for a service coordinator was frequently discussed (Diehl *et al.*, 1991:173,174; Kirk & Glendinning, 2002:630; Molinari & Freeborn, 2006:31; Muggli *et al.*, 2009:59; Young *et al.*, 1988:189). Still, very few parents had access to such a professional. A service coordinator ensures continuity of care and provides parents with a familiar professional to consult with (Kirk & Glendinning, 2002:629; Muggli *et al.*, 2009:59), as well as someone to be an advocate for the family and infant (Kirk & Glendinning, 2002:630).

It is important to realise that the service coordinator can also be the "familiar professional" parents need for counselling (refer to paragraph 3.2.4.3.a) and may satisfy the need for information (refer to paragraph 3.2.4.1). This theme concludes with two statements.

Concluding statement 9: Parents need a service coordinator that is approachable and familiar with the family and infant.

Supporting literature: Diehl *et al.*, 1991:173,174; Kirk & Glendinning, 2002:629-630; Molinari & Freeborn, 2006:31; Muggli *et al.*, 2009:59; Young *et al.*, 1988:189

Concluding statement 10: A service coordinator is a professional who assists parents in organising services, provides support, information and advice and acts as an advocate for the family.

Supporting literature: Diehl *et al.*, 1991:173,174; Kirk & Glendinning, 2002:630; Molinari & Freeborn, 2006:31; Young *et al.*, 1988:189

c. Need for accessible and approachable professionals

This theme relates to *how* parents need professionals, meaning the attitude, knowledge and competency of the professionals. First, parents expressed the desire for professionals to be accessible (Aytch *et al.*, 2001:282; Kerr & McIntosh, 2000:316; Kirk & Glendinning, 2002:632). They reported it is important to have access to professionals to discuss concerns and treatment of the infant, but also to receive quality care from these professionals (Diehl *et al.*, 1991:174; Molinari & Freeborn, 2006:31,33; Moola, 1996:144; Tong *et al.*, 2010:551; Young *et al.*, 1988:190). Being able to discuss concerns with professionals, means professionals should be approachable. Quality service can only be delivered if professionals are knowledgeable.

Honesty and willingness of professionals were valued (Kirk & Glendinning, 2002:628; Konrad, 2007:122; 2002:628; Tong *et al.*, 2010:551), especially where professionals did not have answers or knowledge on the treatment of the infant. Accessible professionals also mean that they provide practical support and hands-on care, which relieves some of the pressure on parents (Kirk & Glendinning, 2002:630-631). This theme is concluded with two statements.

Concluding statement 11: Parents need knowledgeable, accessible professionals to provide quality care.

Supporting literature: Aytch *et al.*, 2001:282; Diehl *et al.*, 1991:174; Kerr & McIntosh, 2000:316; Kirk & Glendinning, 2002:630-632; Konrad, 2007:122; Molinari & Freeborn, 2006:31,33; Moola, 1996:144; Tong *et al.*, 2010:551; Young *et al.*, 1988:190

Concluding statement 12: Parents need honest and approachable professionals with which to discuss their concerns and their infant's condition.

Supporting literature: Aytch *et al.*, 2001:282; Kerr & McIntosh, 2000:316; Kirk & Glendinning, 2002:628,632; Tong *et al.*, 2010:551

d. Need for professional services

This theme relates to services needed from professionals and the availability of these services and how to access them. Parents have the need for different professional services, relating to them as parents and their infants.

Financial assistance was mentioned often in the literature (Bailey *et al.*, 1992:5; Diehl *et al.*, 1991:175; Molinari & Freeborn, 2006:32; Moola, 1996:135; Tong *et al.*, 2010:554). Financial strain is increased through medical expenses, special equipment and specialised care for the children. This need is more evident in mothers of infants in comparison to mothers of school-aged children (Newton, 2006:39). Parents need to know about available grants and how to apply for them.

Having an infant with complex health needs has a big impact on parents and family planning (Tong *et al.*, 2010:554) and parents want to be able to discuss this important aspect and get advice from a professional (Moola, 1996:153). This also relates to the need for counselling (refer to paragraph 3.2.4.3.a).

Quality child care or babysitting services were emphasised by parents (Aytch *et al.*, 2001:282; Diehl *et al.*, 1991:172; McPhee, 2010:82; Young *et al.*, 1988:190). Many parents have the need for this service, but most of them reported not having this service available or that the service was inappropriate to their needs or of poor quality. Although parents needed someone to look after the infant at times, they feared to leave the infant with someone that is not knowledgeable or comfortable with the care of the infant. This made it very difficult for parents to spend time alone with their other children and spouses, go to meetings, run errands or take a break from caring for the infant.

Other professional services included educational, developmental and quality health care. Education is an important aspect for parents. They are concerned about the future of their children and expressed the wish for their children to be in a mainstream school (Moola,

1996:134,140). Although this is not directly related to services for the infant, it is a concern related to the future of the infant (refer to paragraph 3.2.4.1). Quality health care services for their infants are important to parents (McPhee, 2010:78; Molinari & Freeborn, 2006:30; Tong *et al.*, 2010:551) and relate to the theme of approachable and accessible professionals. Parents want the best possible care for their infants from knowledgeable professionals.

One study reported that parents of premature infants did not use early intervention services, services of support for parents, community resources, child care and financial services available to them in the first 6 months after discharge from the NICU (McPhee, 2010:77) although in retrospect the participants of this study did perceive this as a need. This theme concludes with two statements.

Concluding statement 13: Parents need quality, professional services for their children, including child care, medical care and educational services.

Supporting literature: Aytch *et al.*, 2001:282; Diehl *et al.*, 1991:172; McPhee, 2010:78,82; Molinari & Freeborn, 2006:30; Moola, 1996:134,140; Tong *et al.*, 2010:551; Young *et al.*, 1988:190

Concluding statement 14: Parents need financial assistance.

Supporting literature: Bailey *et al.*, 1992:5; Diehl *et al.*, 1991:175; Molinari & Freeborn, 2006:32; Moola, 1996:135; Tong *et al.*, 2010:554

3.2.4.4 Need for self-confidence in the care of the infant

This theme relates to the support parents need in caring for their infant and gaining the self-confidence to do so. The sub-themes of psychological and practical support are discussed and an outline of the analysis of this theme is provided in Table 3-6.

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Table 3-6: Need for self-confidence in the care of the infant - outline of analysis

Main theme: Need for self-confidence in the care of the infant		
This theme relates to the need of parents to be confident in caring for their infant and the support they need to gain this confidence		
Supporting literature	**Sub-theme**	**Theme**
Becoming informed on child's condition and care is empowering Grade II: Diehl *et al*., 1991:174; Kirk & Glendinning, 2002:632; Konrad, 2007:124; Molinari & Freeborn, 2006:32 **Being well-informed increases confidence** Grade II: Konrad, 2007:124	The role of information	Psychological support
Need to be assertive in the care of their child Grade II: Diehl *et al*., 1991:174; Konrad, 2007:125 **Need to be an advocate for the best care of their child** Grade I: Tong *et al*., 2010:551 Grade II: Konrad, 2007:124	Advocate for the infant	
Positive feedback, encouragement, being valued and emotional support by professionals builds confidence Grade II: Kirk & Glendinning, 2002:628,632; Pelchat *et al*., 2004:136 **Need to be included in decision-making process of child's care** Grade II: Diehl *et al*., 1991:174 **Need to be respected** Grade II: Diehl *et al*., 1991:174	The role of professionals	
Need to be taught procedures at home Grade II: Kirk & Glendinning, 2002:632 **Need for hands-on training on equipment function and use at the right time** Grade II: Diehl *et al*., 1991:174	Need for training	Practical support
Need to learn about physiotherapy, medication and monitoring of the child Grade II: Young *et al*., 1988:189	Ability to perform therapies on infant	

This theme was emphasised, although only identified from a few articles. It relates to parents' need to be confident in themselves to be able to care for their infant. It is also closely related to the need for information theme, because information empowers these parents (Diehl *et al.*, 1991:174; Kirk & Glendinning, 2002:632; Konrad, 2007:124; Molinari & Freeborn, 2006:32) and allows them to be an advocate for their infant and to be assertive. Participants reported feeling so strongly about gaining knowledge that they urged other parents to seek information and know everything about the infant's condition and care (Konrad 2007:124).

It is very important to gain confidence in the care of their infant as parents are the main care givers of their children. Parents need support from professionals to become knowledgeable and confident. Professionals provide support through encouraging parents and giving positive feedback, through respecting the knowledge and expertise of parents and including them in the decision-making process of their infant's care (Diehl *et al.*, 1991:174; Kirk & Glendinning, 2002:628,632; Pelchat *et al.*, 2004:136). Parents also need practical support from professionals.

In order to be confident in the care of their child, parents need to know how to physically take care of their child. For this, professionals need to provide practical support through teaching parents how to perform procedures safely and effectively (Kirk & Glendinning, 2002:632), how to monitor the child (Young *et al.*, 1988:189), how to use equipment correctly (Diehl *et al.*, 1991:174) and how to give basic daily therapies like physiotherapy and how to decide on adjusting medication dosages according to the infant's condition (Young *et al.*, 1988:189). This theme concludes with one statement.

Concluding statement 15: Parents need to be confident in the care of their infant. This is achieved through professional support, skills development and knowledge.

Supporting literature: Diehl *et al.*, 1991:174; Kirk & Glendinning, 2002:628,632; Konrad, 2007:124; Molinari & Freeborn, 2006:32; Pelchat *et al.*, 2004:136; Young *et al.*, 1988:189

3.2.4.5 Need for social support

This theme relates to the support parents need from family and the community and an outline of the analysis of this theme is provided in Table 3-7.

Table 3-7: Need for social support - outline of analysis

Main theme: Need for social support		
This theme relates to the support parents need from family, friends, neighbours and the community they live in		
Supporting literature	**Sub-theme**	**Theme**
Relatives, friends and the church community are important sources of support Grade I: Aytch *et al.*, 2001:282; Tong *et al.*, 2010:555 Grade II: Moola, 1996:145-146; Muggli *et al.*, 2009:59; Pelchat *et al.*, 2004:137; Young *et al.*, 1988:190 **Prefer personal resources above professional ones** Grade II: Molinari & Freeborn, 2006:31 **Spousal support is most helpful** Grade II: Young *et al.*, 1988:190	Support person/s	Family support
Acceptance of child by family is important Grade II: Diehl *et al.*, 1991:172 **Lack of understanding from family members were frequently reported** Grade I: Tong *et al.*, 2010:555 **Lack of assistance from family members** Grade II: Moola, 1996:144	Experience of support	
Public acceptance of child is important Grade II: Diehl *et al.*, 1991:172 **Community should be better informed about Down's Syndrome** Grade II: Moola, 1996:148	Expectations from community	Community support
Seek support from the Down's Syndrome Association Grade II: Moola, 1996:143	Source of information	

Parents care for their infants in a familial environment. This makes it crucial for parents that their family supports them and accepts the child (Diehl *et al.*, 1991:172) as it influences their daily environment. Some parents also reported that they prefer the support from personal sources (Molinari & Freeborn, 2006:31).

Although relatives and friends are seen as important sources of support (Aytch *et al.*, 2001:282; Moola, 1996:145-146; Muggli *et al.*, 2009:59; Pelchat *et al.*, 2004:137; Tong *et al.*, 2010:555; Young *et al.*, 1988:190), parents also reported that family members frequently do not understand how it is to care for the child and therefore assistance from family members is lacking (Moola, 1996:144; Tong *et al.*, 2010:555). Sometimes it is also difficult to speak to family members about sensitive topics (refer to paragraph 3.2.3.4.a). Providing parents with written information they can share with family not only satisfies the need for information (refer to paragraph 3.2.4.1), but also improves social support to parents.

Parents seek support from a larger community than just their circle of family and friends and expressed their wishes that the public should be better informed about and accept children with complex health needs (Diehl *et al.*, 1991:172; Moola, 1996:148). This theme concludes with one statement.

Concluding statement 16: Social support and acceptance from family, friends and the community are important to parents.

Supporting literature: Aytch *et al.*, 2001:282; Moola, 1996:145-146; Muggli *et al.*, 2009:59; Pelchat *et al.*, 2004:137; Tong *et al.*, 2010:555; Young *et al.*, 1988:190

3.2.5 CONCLUDING STATEMENTS

Studies of grade I and II, according to ADA (2010:88) (refer to paragraph 3.2.3) , were used for data analysis and therefore for formulating the concluding statements. Concluding statements 1-4, 6, 8, 11-14 and 16 are supported by both grade I and II studies. The other concluding statements are only supported by grade II studies. Concluding statement 1 is the only statement supported by all the studies used for analysis.

1. Parents need information regarding their infant's condition, care, daily routine, medication use, development and future.
2. Parents need information on services, resources and support available.
3. Parents need written information on the care and condition of their infant and information to share with others.
4. Parents need accurate and up-to-date information they can understand.
5. Parents need information at an early stage from a health care professional.

6. Parents need to communicate, share experiences, emotions and information with parents in a similar situation.
7. Parent-to-parent support is the receiving, as well as giving, of support.
8. Parents need to discuss their fears, anxieties and concerns with a familiar health care professional.
9. Parents need a service coordinator that is approachable and familiar with the family and infant.
10. A service coordinator is a professional who assists parents in organising services, provides support, information and advice and acts as an advocate for the family.
11. Parents need knowledgeable, accessible professionals to provide quality care.
12. Parents need honest and approachable professionals with which to discuss their concerns and their infant's condition.
13. Parents need quality, professional services for their child, including child care, medical care and educational services.
14. Parents need financial assistance.
15. Parents need to be confident in the care of their infant. This is achieved through professional support, skills development and knowledge.
16. Social support and acceptance from family, friends and the community are important to parents.

3.3 FIRST POINT OF INTERFACE

At this point of interface the concluding statements of the integrative literature review informed the interview guide (refer to Table 4-1). An interview guide was therefore developed according to topics of the concluding statements and will be discussed in paragraph 4.4.4.

3.4 CONLCUSION

The integrative literature review consisted of five steps. First, a review question was formulated using the PICOT format and then a systematic search was done with predefined key words. The third step was to critically appraise the articles which met the inclusion criteria, where after the data from these articles were summarised and synthesised. The integrative literature review concluded with 16 concluding statements.

Chapter 4: Realisation of the interviews

4.1 INTRODUCTION TO THE CHAPTER

The aim of this study was to explore and describe the support needs of parents of infants with complex health needs in the community. The second objective contributing to this aim was to explore and describe the support needs of parents of infants with complex health needs through interviews in order to provide an emic perspective on the support needs of these parents within the South African context. Individual face-to-face interviews with parents of infants with complex health needs were executed as the second phase of this study (refer to Figure 4-1). In this chapter, the recruitment of the participants, the sampling method, the sample, the interview guide, the field notes and data analysis of the interviews and synthesis of the interviews and integrative literature review, as the second point of interface, will be discussed.

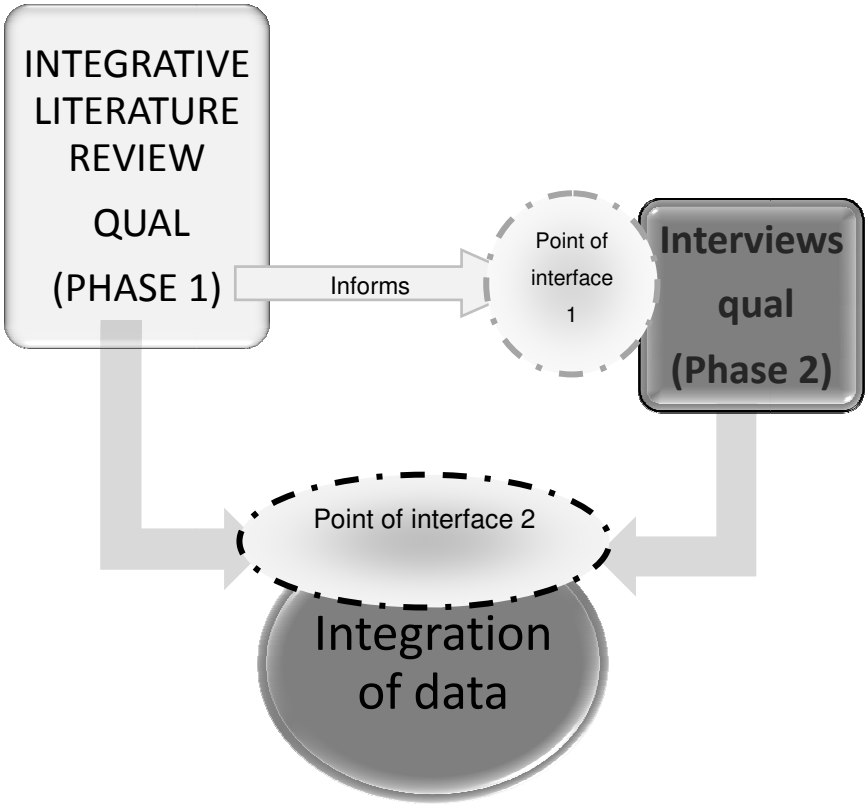

Figure 4-1: Phase 2 - interviews and second point of interface

4.2 RECRUITMENT

Recruitment was done from different socio-economic areas in the community of one of the larger cities in South Africa. Participants were recruited via specialised clinics and day care centres for infants and children with special needs. These centres accommodate infants and children with a range of complex health needs, including genetic and congenital abnormalities.

Centre A is a therapy centre and crèche for infants and children with complex health needs. This centre provides physiotherapy, occupational therapy and psychology services. The registered nurse overseeing the centre was contacted. She in turn received consent from the head of the centre and approached mothers meeting the inclusion criteria of the study. At this centre no mothers with infants under the age of one year agreed to be contacted for an interview, but two mothers with children above one year agreed to be contacted by the researcher. Although the researcher initially excluded participants with older infants, she and her supervisors decided to interview them, but asked them to reflect on their needs during the first year of their infants' lives, since they had valuable information to share. These participants were contacted telephonically, the research study was explained to them and a time was set for the interviews. One participant cancelled the interview, due to time constraints. One participant from this centre was interviewed face-to-face. This participant did not meet the inclusion criteria, as her twins were already two years and seven months old at the time of the interview. However, when asked what her needs were when her infants were still under one year of age, she was able to provide rich information. Her interview was therefore conducted in retrospect and not on her current support needs.

Centre B is a referral clinic for infants with specific congenital abnormalities from three provinces. Patients from around the country and outside South Africa are often referred to this centre. The physician in charge of the centre provided consent that the parents may be recruited from this centre. One of the two registered nurses managing the centre was contacted and she identified participants eligible for this study. Five participants agreed to be contacted by the researcher. Two of the parents could not meet the researcher within the time frame of the study and as a result only three participants were interviewed from this centre.

Centre C serves infants and children with genetic disorders. This centre offers assessment and care for these infants and genetic counselling for the parents. The physician in charge of the centre gave consent for parents to be recruited from the centre and identified participants meeting the inclusion criteria of the study. The participants at this centre have appointments on specific days and was recruited and interviewed the same day they came for their appointment at the centre. Four participants from this centre consented to be interviewed.

A total of eleven participants were recruited, of whom eight consented to be interviewed by the researcher (N=11, n=8).

4.3 THE SAMPLE

Purposive sampling was used since only information-rich participants were recruited for the interviews so that they could provide insight on the research phenomenon (Onwuegbuzie & Leech, 2007:111). Criterion sampling was utilised as purposive sample strategy as described by Onwuegbuzie and Leech (2007:114) with the following inclusion criteria: parents of infants under the age of one year, with complex health needs and cared for at home. The sample was limited to participants available and accessible at the time the study was conducted. The ages of the infants ranged between two and nine months at the time of the interview, except for one participant's infants who were above one year of age as discussed in paragraph 4.2.

Participants agreeing to be interviewed were only mothers. The participants' ages ranged between 20 and 40 years (mean age 30.13 years). The sample included participants from different cultural and socio-economic backgrounds. For five of the participants this was their first child, but the other participants also had other children. Five of the eight participants were in a marital relationship. The participants had infants with different complex health needs including complete bilateral cleft lip and palate, Down Syndrome, epilepsy, multiple congenital abnormalities, Pierre Robin Syndrome, prematurity, severe developmental delay and Van der Woude Syndrome.

The interviews in this study provided qualitative data as a strategy to enhance the results of the integrative literature review and therefore data saturation was not attempted. Still, the researcher and her supervisors theoretically specified an initial sample of eight as adequate in representing diversity (Francis *et al,* 2010:1234).

4.4 THE INTERVIEW PROCESS

The discussion of the interview process will include the time, place and length of the interviews, the contractual relationship with the participant, the interview guide, the interviews and transcription of the interviews. This process has been outlined in paragraph 2.4.4, but will now be discussed in full.

4.4.1 ARRANGING THE INTERVIEWS

The time, location and length of the interviews were considered in arranging the interviews.

Time: Four of the eight participants were contacted telephonically to organise a time for the interview that suited them. These appointments were made in the allocated time set aside for data collection. The remaining four participants were only contacted on the day of the interview. On the day of the interview, the study was explained to the participants and they were provided with their own copy of the consent form.

Location: The interviews were conducted at different locations, as it was suitable for the participants. Three interviews were conducted at the participants' home, one at the participant's work place and four at Centre C, where the participants visited with their infants. In six of the interviews the infants were also present during the interview. Precautions were taken to ensure privacy with the five interviews not conducted at the participants' home. Although these five interviews were conducted in private areas, it was still noisy and not secluded. This influenced the quality of the voice recording in interviews four, five, six and seven and it was necessary to rely on the field notes as well as on the interview transcripts in order to present these interviews truthfully.

Length of the interviews: The time allocated for the interviews were 30 to 60 minutes, however, seven of the eight interviews were completed within 30 minutes after which time no new information became available. The next step of the interview process was to establish a contractual relationship with the participants.

4.4.2 CONTRACTUAL RELATIONSHIP WITH PARTICIPANTS

On meeting the participants the researcher introduced herself and explained the aim of the study to the participants. The researcher communicated to the participants that their information may contribute to health care professionals better understanding the needs of parents of infants with complex health needs and thereby offering improved support. After explaining the rights of the participants, the use of a digital recorder and the informed consent form to the participants, each participant signed a written consent form. The participants also received a copy of the consent form, which contained information on the study and the researcher.

4.4.3 THE INTERVIEWS

Focussed interviews were conducted. All interviews were conducted by the same researcher in the same manner. Every interview was started with the same interview question as discussed in paragraph 4.4.4.

Initially a pilot interview was conducted, after which the interview was discussed with the study supervisors before more interviews were conducted. After discussing the pilot interview with the study supervisors, some changes were made for the following interviews. Firstly, the researcher took care not to ask leading questions, but rather to focus more on probing the participant. Secondly, a more relaxed atmosphere was created by means of an informal, general discussion before the actual interviews were started. Voice recording was already started during this discussion to put the participant at ease and make the voice recording less obvious. The voice recorder was left recording after the interviews were concluded, as sometimes extra information was shared by the participants during this time. Lastly, it was decided, if possible, to send the first question of the interview and the themes to be discussed to the participants before the interview so that participants could prepare for the interview. The pilot interview is referred to as interview one in the rest of the discussion of the interviews.

For interviews two, three and eight the interview question and themes to be discussed were sent via e-mail to the participants two to four days before the interview. Interviews four to seven were not by appointment and the participants did not receive information on the interview guide beforehand. This did have an effect on the quality of these interviews as the participants were not prepared and sometimes struggled to answer or understand the interview questions.

In three of these interviews language was also a barrier. The interviews were not conducted in the participants' first language and they had difficulty in understanding some of the questions and also in expressing themselves. The researcher often rephrased questions and sometimes gave an example to clarify questions in order for the participants to understand. Reflection was a technique used in all the interviews to ensure that the researcher understood the participants correctly.

4.4.4 INTERVIEW GUIDE

The interview guide was informed by the concluding statements derived from the integrative literature review as the first point of interface. All interviews were initiated with the main question:

"Can you please describe your most important need as parent in caring for your child?"

The answer of the participants in response to this question guided the interview and was explored. At the end of discussing this question, the participants were asked to specify which one of these needs they described was most important to them. The results of the integrative literature review were then shortly explained to the participants and they were asked to share their experience related to the topics of the concluding statements. The interview guide is provided in Table 4-1.

Table 4-1: Interview guide

Main interview question	
Can you please describe your most important need as parent in caring for your child?	
Themes to be discussed	**Probing questions**
Need for information	Can you describe what information you feel you need? (Prompts: child's condition, care, medication, development, future, services, resources and support available) How do feel about information on service delivery? How would you like to receive information? When would you have liked to receive information? From whom would you like to receive information?
Need for parent-to-parent support	How did meeting other parents in a similar situation make you feel? When/how would you have liked to meet other parents in a similar situation? What will you like to share with other parents?
Need for professional support	How did counselling support/help you? Who counselled you? (prompts: did you receive counselling? would you want to?) Who is the professional you turn to if you have questions or concerns? Who referred you to services and helped you find resources? What is the quality of care you hope to receive from professionals? What other services than medical services do you need? (prompts: day care, babysitting services) How was your finances affected by caring for your infant?
Need for self-confidence in the care of the infant	Describe your confidence level in caring for your infant. What gives you confidence in caring for your infant?
Need for social support	Who are important support systems to you? (prompts: family/friends/spouse/church) How do people react towards your infant?

The interview guide was not a strict set of questions to be followed, but rather a guide to explore the themes of the integrative literature review if it did not naturally evolve from the interview question. Therefore not all the questions of the interview guide were asked to all the participants.

At the end of the interview the discussion was summarised by the researcher and the participants were asked if they wanted to add anything else. The interview was concluded by thanking the participants for their participation. The next step was to transcribe the interviews.

4.4.5 TRANSCRIPTION OF THE INTERVIEWS

The voice recorded interviews were transcribed verbatim before data analysis started. The interviews were transcribed by a transcriber who understands the importance of anonymity and confidentiality of the information. After transcription the researcher listened to all the interviews and compared that to the transcripts. During this phase the transcripts were corrected and enhanced by the field notes, especially those of poor recording quality. The field notes made it possible to remember some parts of the conversation that was not audible on the recording. The transcribed interviews are available in ADDENDUM 3-1.

4.5 FIELD NOTES AND REFLECTION ON THE INTERVIEWS

Field notes are a written account of things during and around the interview (Botma *et al.,* 2010:217*)* taken by the researcher during or after data collection. Descriptive and reflective notes (Creswell, 2009:181-182) were taken directly after each interview (Botma *et al*., 2010:218) on different aspects of the interview. This was done to ensure accuracy and completeness of the notes, as well as to describe the context of the interview. It was furthermore used during analysis if the voice recording was of poor quality. It was therefore taken for analytical and descriptive purposes. Salience hierarchy was utilised to write the field notes and is described as only noteworthy observations and therefore not detailed (Wolfinger, 2002:89). It was subjective and influenced by the background knowledge and worldview of the researcher (Mulhall, 2003:310; Wolfinger, 2002:90).

Observational notes were taken on the date and place of the interview and included the interview environment (Polit *et al*., 2001:283). In these notes the main discussion areas were recorded, as well as any interruptions, for example attending to the infant. *Theoretical notes* attempted to interpret what some of the observations meant or how it related to the dialogue (Polit *et al*., 2001:283). The *methodological notes* documented reminders on the process of observation or how observations should be changed during the following interviews (Polit *et al*., 2001:283). Finally, the *personal notes* commented on the researcher's own feelings and thoughts (Polit *et al*., 2001:283). An example of the field notes of this study is available in ADDENDUM 4-1.

Five of the participants were very nervous about the interview. Most of them relaxed as the interview progressed, but the seventh participant was uncomfortable throughout the interview and therefore struggled to convey rich information on the interview subject. She admitted that when her infant was born it was very difficult for her to talk about the infant's condition and it appeared to be difficult even now. This participant did not respond to probing and the interview was therefore short in duration. The participants of interview two, three and eight were relaxed

and almost excited about being able to share their information. These participants shared as much information as possible, but unfortunately interview eight was cut short due to time constraints of the participant.

It is noteworthy that the participants with the older infants seemed to share information more easily and appeared more relaxed. This may be due to different reasons, including that they might be more aware of their needs and that they have already accepted their situation and therefore find it easier to talk about it.

The analysis of the interview data and synthesis of the interviews and integrative literature review are discussed next.

4.6 ANALYSIS AND SYNTHESIS OF THE DATA (SECOND POINT OF INTERFACE)

Thematic analysis was done on the data using an analytical framework (refer to Table 4-2). The themes used were those developed in the thematic analysis of the integrative literature review. As the interviews were a strategy used to contextualise the findings of the integrative literature review, it was appropriate to use the same themes. Still, to reduce bias, data not fitting into these themes were not ignored, but still analysed for new or contradicting themes. Consensus was reached with the independent reviewer on the identification of themes, including additional themes.

Table 4-2: Analytical framework utilized for analysis of interviews

Main themes	Sub themes
Need for information	Types of information Communication
Need for parent-to-parent support	
Need for professional support	Counselling Service coordinator Accessible and approachable professionals Professional services
Need for self-confidence in the care of the infant	
Need for social support	Family support Community support
New themes	

Analysis was done according to the six steps suggested by Creswell (2009:185-189). The *first step* in analysis was to organise the interview data through transcribing the interviews and

typing the field notes. The *second step* involved reading and re-reading the transcripts to get a general sense of the interviews.

Thereafter coding of the text started during the *third step*. Colours were allocated to each of the pre-existing themes from the integrative literature review. While reading the transcripts, text applying to a certain theme was highlighted with the associated colour. Each interview was therefore analysed in terms of the analytical framework developed from the findings of the integrative literature review. Sections that did not fit into the analytical framework were marked and later developed into an additional theme. Statements from the interviews were used for analysis even if the participant only mentioned it once or did not elaborate on it, as long as it was related to the research question (Braun & Clarke, 2006:82). If the same code appeared again in the same or other interviews, it was not taken down repetitively, as the goal of analysis was not to count the themes, but to report which themes related to the research question, were present in the data (Braun & Clarke, 2006:83). This type of analyses is called topic coding (Richards, 2005:88, 92) where passages of data are interpreted according to their topic. The field notes were also utilised for analysis through colour coding.

The *fourth step* involved description and development of an additional theme - the need for normality. The need for normality was defined according to the interview transcripts and did not realise from the integrative literature review. During this step text contradicting some of the concluding statements of the integrative literature review was also described. Concluding statements not supported by the interview transcripts were identified.

The *fifth and sixth* steps were combined to report the findings of the interviews and synthesise the results of the integrative literature review and interviews (refer to paragraph 4.7) as the second point of interface (refer to Figure 4-1). During these steps the data were represented through narratives from the transcripts. The data were also interpreted and supported by literature from the integrative literature review. The new theme, although not identified in the integrative literature review, is supported by literature (refer to paragraph 4.7.6)

4.7 FINDINGS

The integration of the findings of the integrative literature review and the interviews are discussed according to the themes identified in the integrative literature review. Any quotations used from Afrikaans interviews were freely translated into English by the researcher. Figure 4-2 is a summary of the themes discussed and how these themes relate to each other.

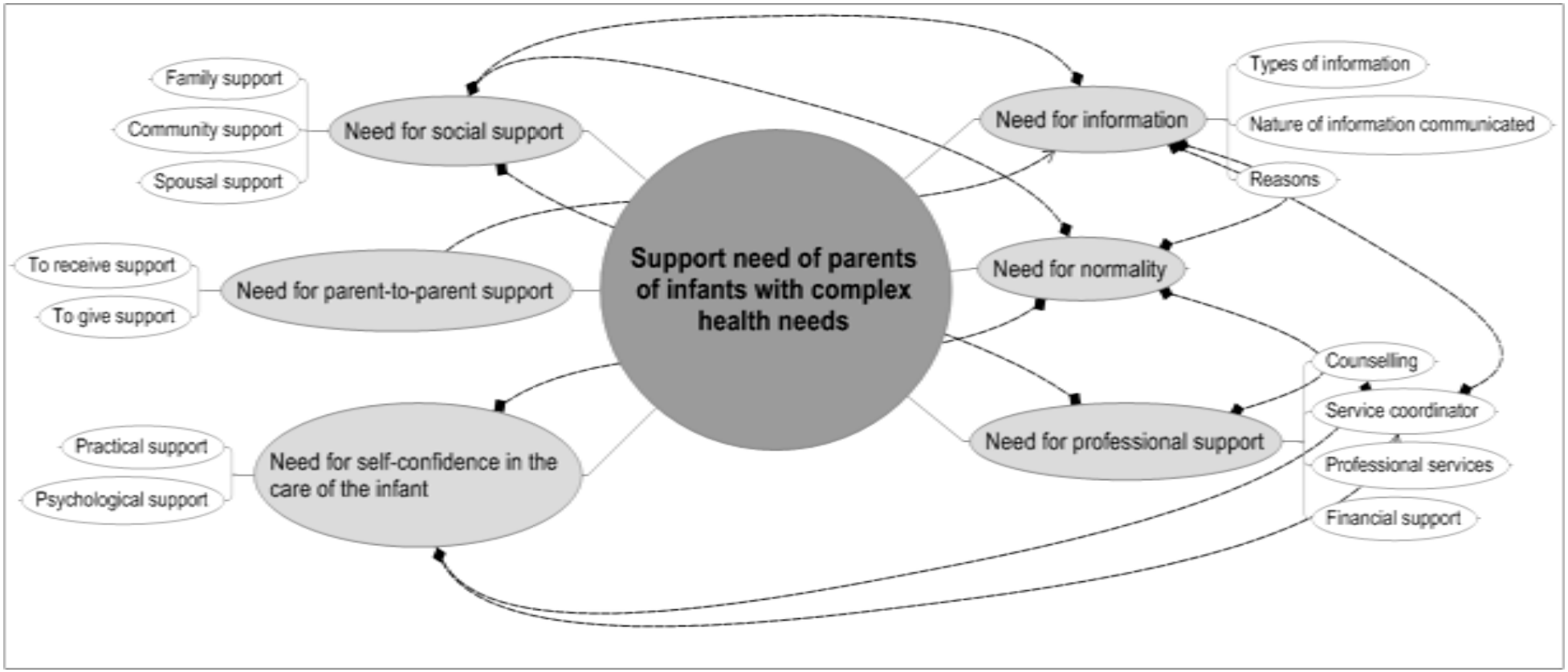

Figure 4-2: Main themes identified with interviews analysis and how they relate

4.7.1 NEED FOR INFORMATION

This theme was expressed in both components of the study. All the participants interviewed reported that they needed information. Some of the aspects specifically identified were the need for information on medication administration (interview 2), the condition of the infant (interview 1, 3, 4, 5, 6 & 7), what to expect from the future (interview 2 & 6), resources and services available (interviews 2, 3 & 8) and daily care (interviews 1, 6 & 7). This correlates with the information needs identified in the integrative literature review (refer to paragraph 3.2.4.1) and is related to the concept of lifetime growth of the modelling and role modelling theory where accurate information assists parents in change and decision-making (refer to paragraph 1.7.3).

Participants of the interviews reported different views on future expectations. Although many participants do wonder about the future, some want to know what to expect from the future (interviews 2 & 6), but still rather do not think about the future too much (interviews 2, 3 & 7) as it makes them worry. This is clear from the remark of the second participant when asked if she ever thought about the future.

"Oh, every day, every day. But just time and again I'm pulled back and say take it day to day...And then, will she be okay with speech therapy? Will she be okay at school one day, will she, you know, will they accept her...?" Interview 2

Information on the condition of the child was a theme emphasised in the integrative literature review and interviews. Participants of the interviews wanted to know what the cause of the condition was, what it means to have this condition and how to adjust daily care giving of the infant (interviews 1, 3, 4, 5, 6 & 7), correlating with other parents' needs according to the literature (Aytch *et al.*, 2001:282; Bailey *et al.*, 1992:5; Diehl *et al.*, 1991:173,177; Kerr & McIntosh, 2000:314; Kirk & Glendinning, 2002:632; McPhee, 2010:80; Molinari & Freeborn, 2006:32; Moola, 1996:132,183; Newton 2006:40; Pelchat *et al.*, 2004:134; Tong *et al.*, 2010:555; Young *et al.*, 1988:189). Participants reported being scared and shocked with the diagnosis of their infant, because they did not know what it meant.

"Yes, I was scared...They told me my baby did have low ears, flat nose...I don't know what it means" Interview 5

Information reduces fear and anxiety (interview 3) if it is understandable, otherwise it may cause frustration (interview 8). Both the participants (interviews 1, 2 & 8) and the literature identified specific, understandable and personalised information as important information needs of parents of infants with complex health needs (Aytch *et al.*, 2001:282; Diehl *et al.*, 1991:173; Kirk & Glendinning, 2002:632; Muggli *et al.*, 2009:59; Kerr & McIntosh, 2000:314; Pelchat *et al.*, 2004:134; Tong *et al.*, 2010:553). However, the participants of the interviews did not specify that

they needed information at an early stage like the participants of two studies of the integrative literature review did (Muggli *et al.*, 2009:59; Pelchat *et al.*, 2004:134).

Although the interviews confirmed that there was a need for accurate and correct information, participants differed on how they wanted to receive this information. Five of the participants voiced the need for written as well as verbal information, while the remainder were satisfied with verbal information and education only. It appeared that the participants satisfied with only verbal information were those of lower socio-economic background, but it may also be that verbal information alone was enough to make them feel well-informed (Tomlinson *et al.*, 2011:761). The quotes below illuminate the contrast.

"I literally gave them a stack and said this is for you, read so that you can know what is what...But I think information, physical information which you can read, because you know, when you visualise something when you read something, it goes more into your brain as when you talk about it." Interview 3

"Doctor came and explained....She showed me, talked...yes [I feel satisfied]" Interview 5

Information was not easy to find (interviews 1, 2 & 8) and participant eight described that she had to "dig" for information. Participants from the interviews specifically needed information on services available and how to access them (interviews 1, 2, 3 & 8) as reported in literature as well (Aytch *et al.*, 2001:282; Bailey *et al.*, 1992:5; Diehl *et al.*, 1991:173; Kirk & Glendinning, 2002:632; Molinari & Freeborn, 2006:32; Moola, 1996:139; Pelchat *et al.*, 2004:134; Tong *et al.*, 2010:555). The second participant also wanted more practical demonstration on certain techniques in caring for her infant, as she reported that they see a professional often enough to make this possible.

It is interesting to observe how each participant knows which information they need and what they did to obtain this information. They therefore utilises their self-care knowledge and resources, a concept which is referred to as self-care action (refer to paragraph 1.7.3). Considering both components, it can be concluded that parents of infants with complex health needs in a South African context do have the need for understandable information on different aspects of their infant's condition and care, but do not necessarily need written information. Figure 4-3 and Figure 4-4 provide a visual presentation of the analysis of the need for information.

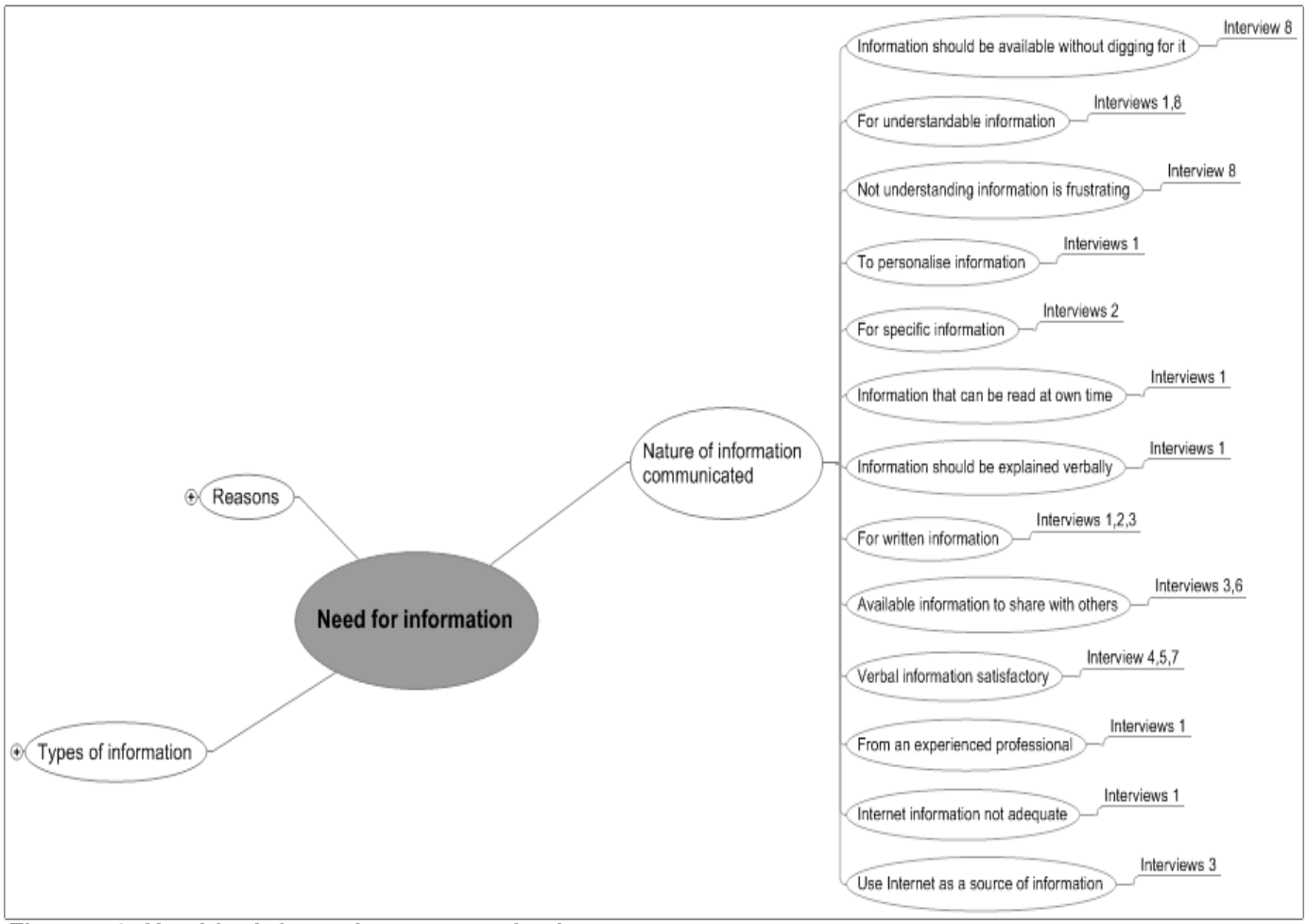

Figure 4-3: Need for information: communication

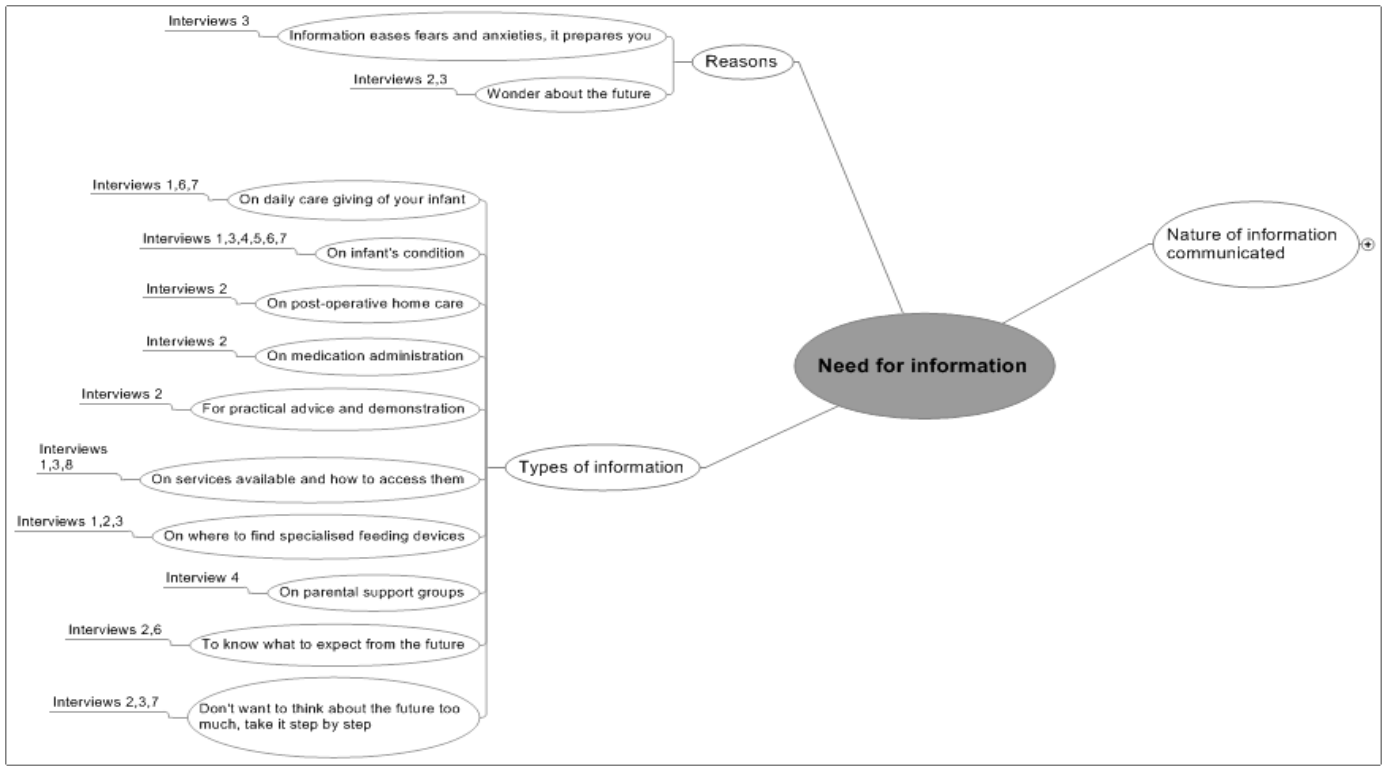

Figure 4-4: Need for information: types of information and reasons

4.7.2 NEED FOR PARENT-TO-PARENT SUPPORT

This theme from the integrative literature review was well supported by the participants of the interviews. All of the participants communicated that they had the need to meet other parents in a similar situation. It was described often that meeting these other parents made you feel "less alone" (interviews 1, 2, 4, 6, 7 & 8). This statement was also made by some of the participants of a study of the integrative literature review (Kerr & McIntosh, 2000:317) and is portrayed in the statements below.

"...I actually realised how many parents there actually is..." Interview 1

"...you feel very sorry for yourself and then it just strikes you that you are not the only one, there is other moms that have also come through this..." Interview 2

"I feel like better, like I'm not alone." Interview 5

"I don't sit back. I say that I'm not alone." Interview 6

In addition to feeling less alone, participants also reported that other parents understand you the best (interviews 1, 3 & 8) as you share similar situations. Therefore by meeting and speaking to these parents, the participants reported feeling comforted, reassured and encouraged (interviews 1, 2, 3, 4 & 6), as reported by participant four below.

"It's so good because it hurts and then. And then I feel comforted." Interview 4

This reassurance has also been described in the literature (Konrad, 2007:121; Aytch *et al.*, 2001:282). One participant strongly suggested that new parents should not be the ones seeking support, but that support from other parents should be offered to them, as it is very difficult in the beginning to ask for help or support (interview 2). This relates to the same participant reporting that support should therefore not be offered to soon after diagnosis of the infant, as the parent is then not yet comfortable discussing the situation with anyone.

"I'm not one of those, I mean it was very hard for me in the beginning to know that she was born with [the condition]. It was until I didn't, I don't want to say accept, but until I half got over it, then it was better for me to talk about it and I must say it probably took me about a month. And then it doesn't help somebody talks to you." Interview 2

Participant eight reported that although she needed to meet other parents, it is difficult to attend meetings, because all the parents are busy and it is difficult to organise babysitting services for the infant. Meeting other parents in a similar situation gives parents not only the opportunity to

receive support, but also to give support through sharing of information and encouragement (interviews 2, 3, 4, 5 & 6).

By integrating the results of both components of this study it can be concluded that parent-to-parent support is needed by parents of infants with complex health needs in a South African context. Figure 4-5 provides a visual presentation of the analysis of the need for parent-to-parent support theme.

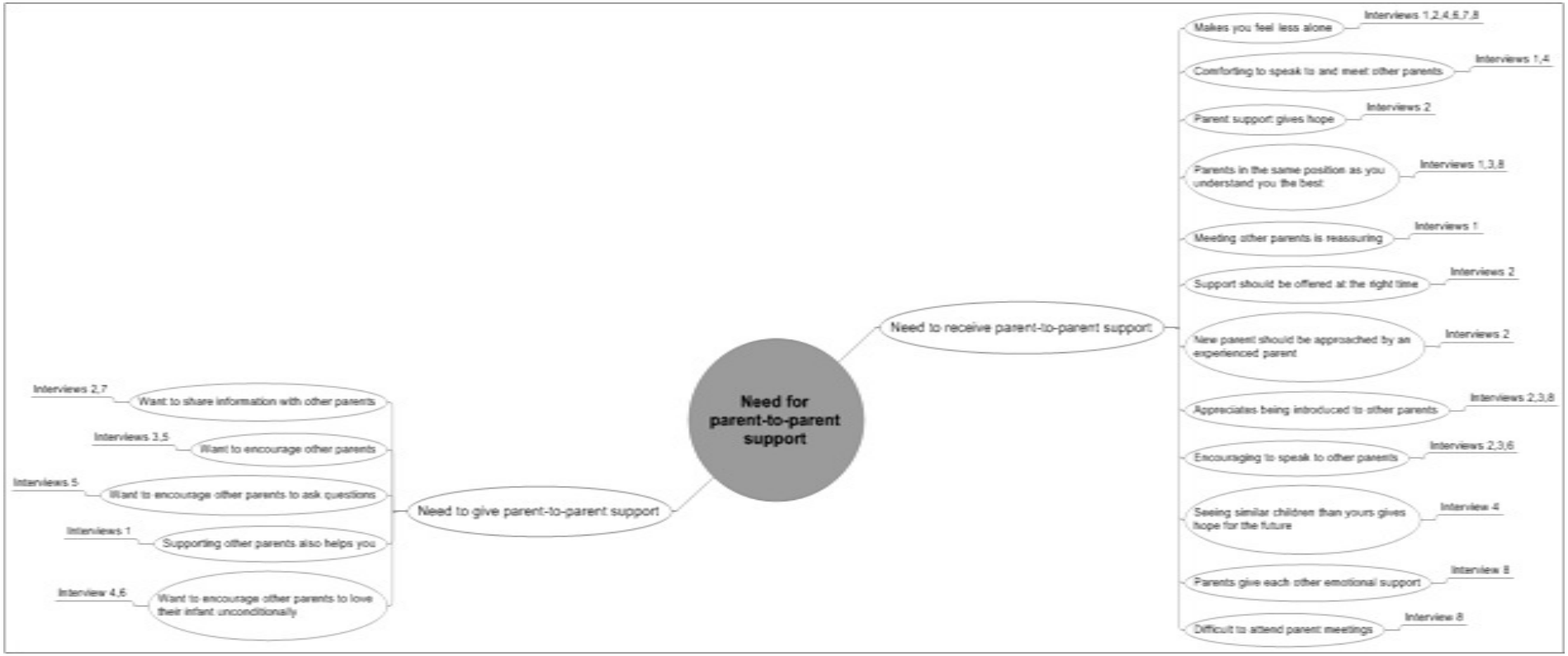

Figure 4-5: Need for parent-to-parent support

4.7.3 NEED FOR PROFESSIONAL SUPPORT

The need for professional support was mentioned by all the participants in the interviews. Using the integrative literature review results as a guide, the need for professional support will be discussed in four sub-themes: need for counselling, need for approachable and available professionals, need for a service coordinator and the need for professional services.

4.7.3.1 Need for counselling

The need for counselling was expressed by the participants in the studies analysed in the integrative literature review (Aytch *et al.*, 2001:282; Diehl *et al.*, 1991:177; Kirk & Glendinning, 2002:629; Molinari & Freeborn, 2006:32; Moola, 1996:152; Newton, 2006:40; Pelchat *et al.*, 2004:133). This included parents' need to express their fears and anxieties, discuss concerns and to come to better insight about their situation. As illustrated in Figure 4-6, participants of the interviews also expressed this need (interviews 1, 2 & 5), especially as they felt at fault for the condition of the infant (interview 1 & 2), as portrayed in the statement below.

"...I blamed myself and had self-blame and...I just needed someone close or someone, I would have liked to be able to talk to someone who actually sort of had the knowledge and that."
Interview 1

Figure 4-6: Need for professional support: counselling

Counselling resolved feelings of guilt and helped with acceptance of the situation (interview 2). The third participant did not report the need for counselling for herself, but rather for the

grandparents of the infant. She did, however, report the need for genetic counselling, as did the participant of interview seven.

4.7.3.2 Need for a service coordinator

This sub-theme was clear from both phases of the study and an analysis is provided in Figure 4-7. A service coordinator was described as invaluable (interviews 2, 3, 5 & 8) by the participants of the interviews and they expressed the importance of an available professional they may contact at any time and discuss anything with (interviews 1, 3 & 8).

"Those two ladies are like gold in a person's life..." Interview 2

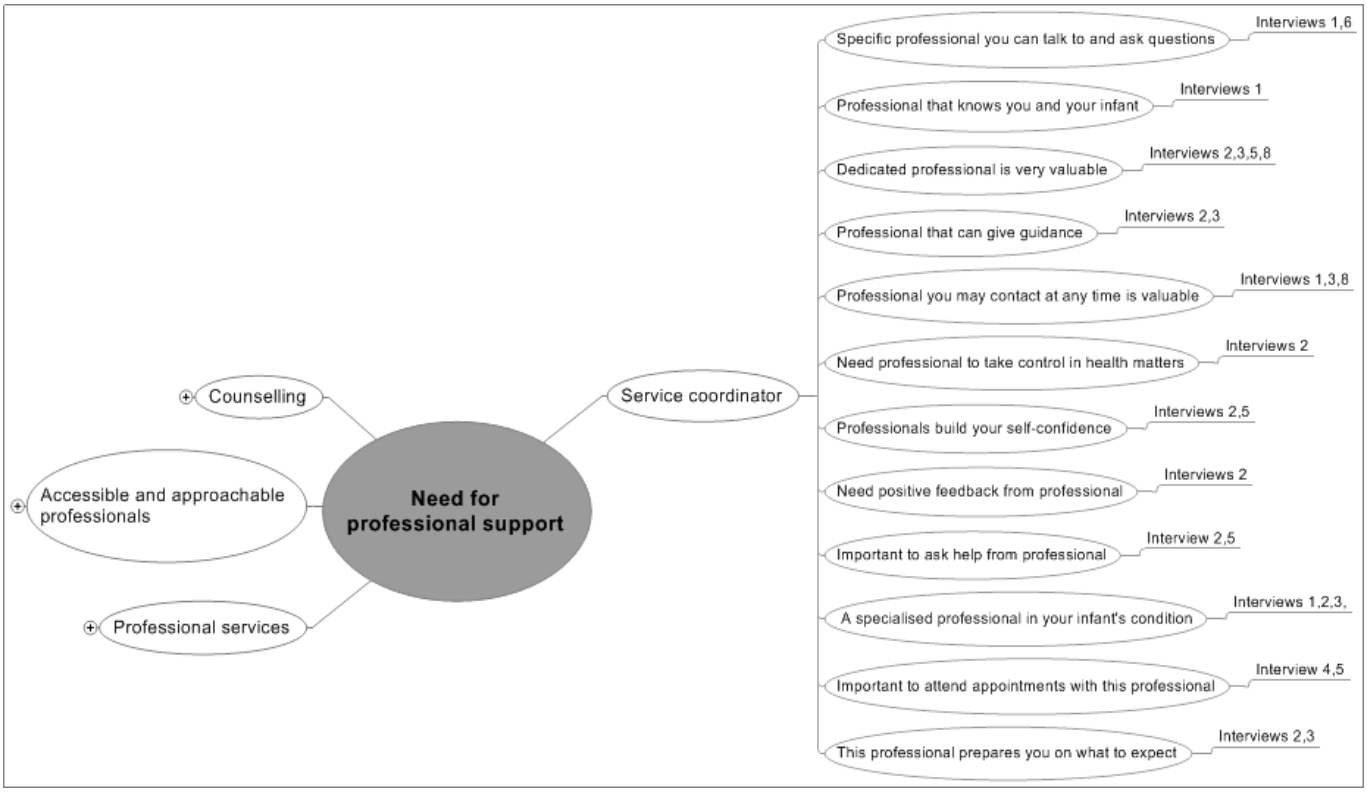

Figure 4-7: Need for professional support: service coordinator

The appreciation of the availability of such a professional as a service coordinator was also expressed by the participants of the study of Kirk and Glendinning (2002:629). The participants from the second and third interviews and the literature (Muggli *et al.*, 2009:59) describe this professional as giving guidance. Participants of interviews one to seven also mentioned a professional in the role of service coordinator as their main source of information.

Emotionally the service coordinator builds the participants' confidence (interviews 2 & 5), gives positive feedback (interviews 2) and prepares them on what to expect from the future

(interviews 2 & 3). This correlates to how the participants of Kirk and Glendinning (2002:629-630) describe the services coordinator as an advocate and being available for them.

4.7.3.3 Need for accessible and approachable professionals

This sub-theme relates to the need for available and competent professionals. Participants expressed that there were too few specialised professionals available to deliver services to them (interview 2 & 8). This increased the waiting time to consult with a specialist and receive services (interview 8), increased the travelling distance for services (as there are not necessarily services available in their area) and made it difficult to consult another professional for a second opinion (interview 2). The effort it took to be seen by a specialist shows in the following quote.

"You know what? I kept on calling, I reached doctor A. And I had to just at a stage. Because we were so desperate about the [condition] that we had to see a neurologist. And that was December, then they said to me they can see me in March. Then I thought well I will have to wait...That was the only guy I could get in at. And in the mean time I started phoning around and see if there wasn't somebody with cancellations or something. And then I reached doctor B. And her receptionist then told me there is a new doctor who just qualified...And that is how we got in, because they told me if I want to get in at the government that I will have to wait seven months."
Interview 8

Participants of the studies analysed in the integrative literature review expressed the need for accessible professionals (Aytch *et al.*, 2001:282; Kerr & McIntosh, 2000:316; Kirk & Glendinning, 2002:632), but also for quality service from professionals (Diehl *et al.*, 1991:174; Molinari & Freeborn, 2006:31,33; Moola, 1996:144; Tong *et al.*, 2010:551; Young *et al.*, 1988:190). This relates to the needs reported by the participants of the interviews that they needed professionals to be knowledgeable (interview 1 & 2), not prescribe unnecessary medication (interview 2), be sensitive towards you (interview 2), have enough time to spend with you and your infant (interview 8) and give you feedback on tests done (interview 8). For the participants of the interviews, having access to professionals also meant being referred to the correct professionals (interview 2 & 8). Figure 4-8 illustrates the analysis of this sub-theme.

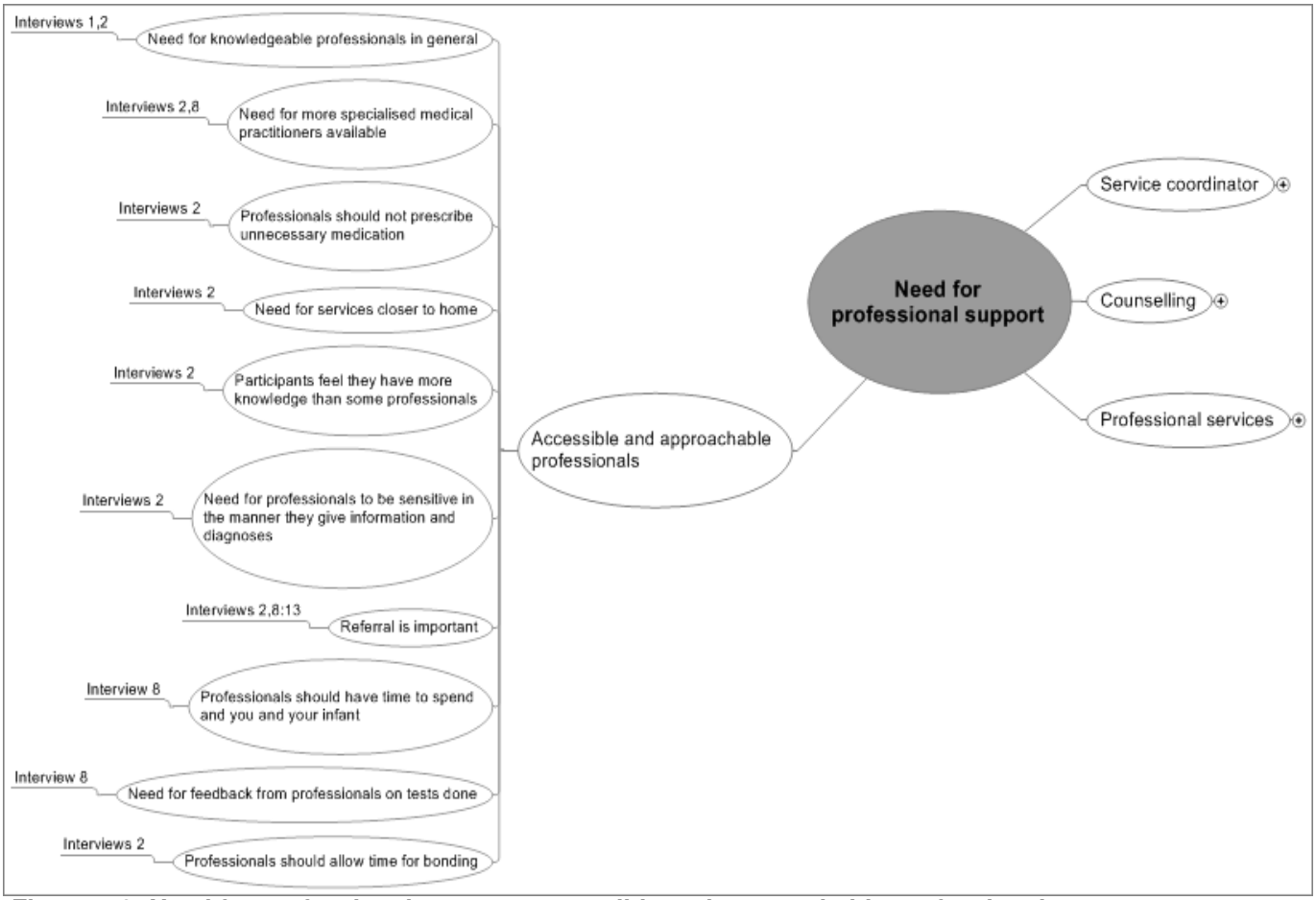

Figure 4-8: Need for professional support: accessible and approachable professionals

4.7.3.4 Need for professional services

The fourth sub-theme was the need for professional services (refer to Figure 4-9). The integrative literature review identified that participants in the stated research needed financial support and services (Bailey *et al.*, 1992:5; Diehl *et al.*, 1991:175; Molinari & Freeborn, 2006:32; Moola, 1996:135; Tong *et al.*, 2010:554), quality child care services (Aytch *et al.*, 2001:282, Diehl *et al.*, 1991:172; McPhee, 2010:82; Young *et al.*, 1988:190), family planning services (Moola, 1996:153) and educational, developmental and health care services for their infant (McPhee, 2010:78; Molinari & Freeborn, 2006:30; Tong *et al.*, 2011:551).

One of the needed services that parents emphasised in the interviews is the availability of child care for the infant (interview 1, 2, 3 & 8). Participants felt uncomfortable leaving their infant at day care (interview 1, 2 & 3) and mostly relied on family members for babysitting (interviews 1, 2, 3, 4, 5, 6 & 8). This was also due to the difficulty in locating day care services that is suitable for infants with complex health needs (interview 8). Most of the participants opted for their infant to be looked after at home.

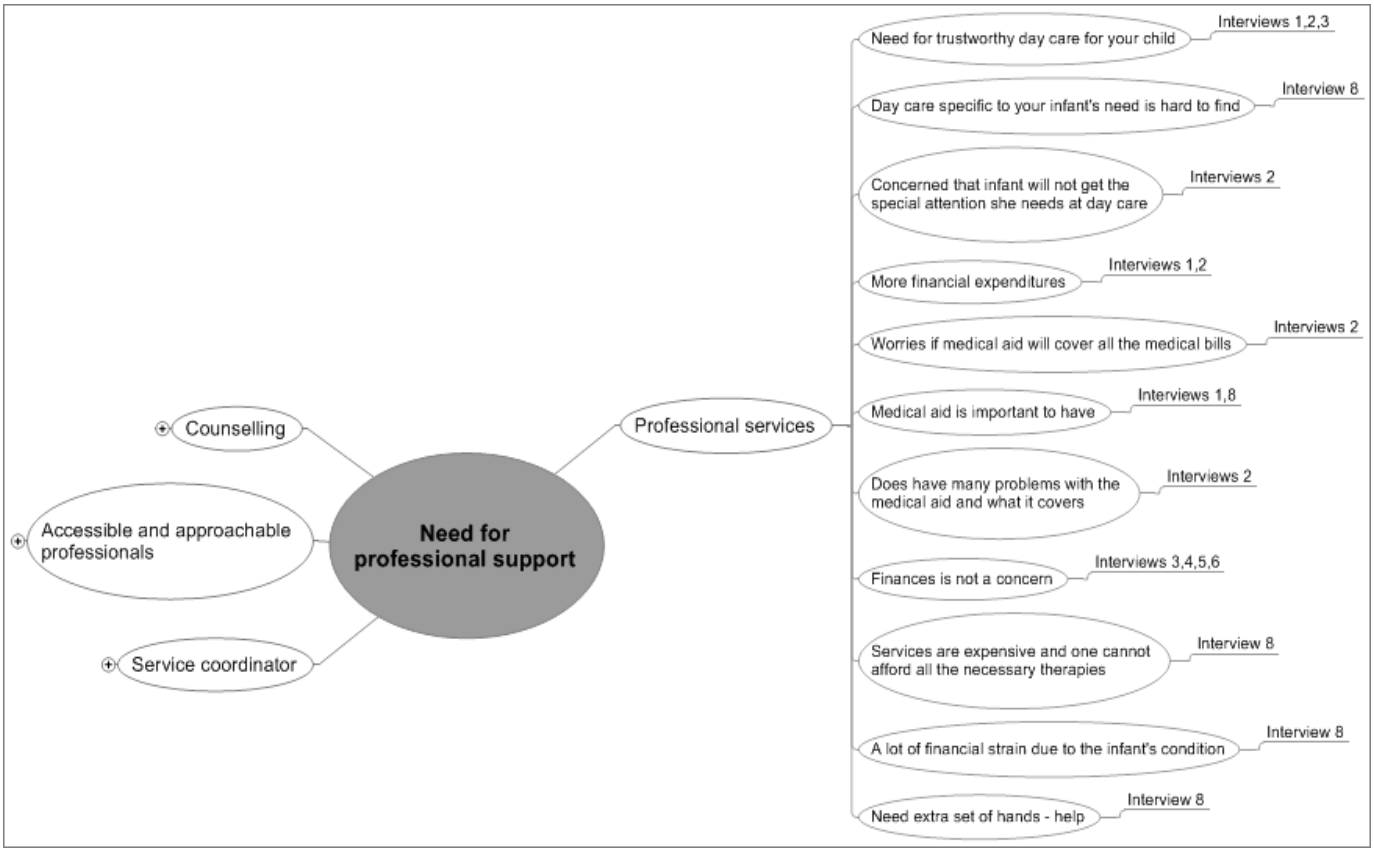

Figure 4-9: Need for professional support: professional services

Participant eight emphasised "an extra set of hands" as her greatest need. Although she also relied on family members to fulfil this need, she expressed the wish for this person not to be a family member. She described that it is sometimes difficult to tell a family member what to do and how you would like things to be done. She further expressed that you do not want to burden family members. The lack of services available to these parents puts extra strain on their social support system as portrayed in the statement below.

"Yes, it's not pleasant and many times I feel my life is such a rush that I almost just talk to [my mother-in-law] when I need her...It feels bad because it feels like I'm using her." Interview 8

Not having this resource available places a lot of strain on another sub-system (the social support structure) in order to cope and can therefore lead to maladaptation according to the modelling and role modelling theory (Erickson *et al.*, 1983:47).

The need for financial assistance was not expressed by the interview participants, although some participants did report extra financial expenses (interview 1 & 2) and one reported much financial strain (interview 8). This is in contrast with findings of the integrative literature review, which concluded that parents of infants with complex health needs needed financial assistance (Bailey *et al.*, 1992:5; Diehl *et al.*, 1991:175; Molinari & Freeborn, 2006:32; Moola, 1996:135; Tong *et al.*, 2010:554). This may be due to the differences in how medical expenses are

covered in the different countries. Developed countries have funding available for grants, equipment and supplies; where in South Africa funding is scarce. This may lead to participants of the interviews not expecting any assistance from the government and therefore they do not report the need for it, in contrast with developed countries. Regarding finances, two participants discussed the difficulties they had with medical aid and the covering of medical costs (interview 1 & 2) and two participants expressed the importance of medical aid (interview 1 & 8).

By synthesising the results of the components of this study, it can be concluded that parents of infants with complex health needs in a South African context do need counselling, a service coordinator, approachable, accessible and specialised professionals and professional services for them and their infant.

4.7.4 NEED FOR SELF-CONFIDENCE IN THE CARE OF THE INFANT

Participants of the interviews emphasised that information increased their confidence as knowledge empowered them to care for their infant (interview 1 & 8), which has also been stated elsewhere in the literature (Diehl *et al.*, 1991:174; Kirk & Glendinning, 2002:632; Konrad, 2007:124; Molinari & Freeborn, 2006:32). In turn, the more they use their knowledge to care for their infant, they see improvement and it builds their confidence (interview 6 & 7). This theme is therefore directly related to the need for information. Information includes practical support, as recognised in the integrative literature review (Diehl *et al.*, 1991:174; Kirk & Glendinning, 2002:632; Young *et al.*, 1988:189), in order to physically care for their infant (interview 1 & 2).

Desiring information to gain confidence in caring for their infant is directly related to the unique concept of affiliated-individuation of the modelling and role modelling theory (refer to paragraph 1.7.3). Participants are therefore dependent on information and support to enable them to care for their child, while striving to be independent and being able to care for their infant on their own.

The participant of the second interview expressed that as you learn to accept the situation, you find it easier to admit if you need support and ask for help, which in turn increases your confidence. This indirectly relates to the need for counselling, as counselling may lead to acceptance of the situation. Part of the acceptance is, as expressed by participants (interviews 2, 4 & 5), the knowing that God is a God of love, that He loves you and your infant and that this infant is not a punishment from God.

"...In the beginning I thought I'm punished by God, but my family said no, God loves you. I don't have to blame myself." Interview 5

Bonding was emphasised as important in improving self-confidence. One participant said she felt incapable of handling her infant at home (interview 2), as she never got a chance to bond with or care for her infant while still in hospital. In contrast with this another participant reported that she thinks bonding is much better with her special needs infant than a normal infant, as you are forced to spent more time in caring for the infant (interview 3). This is supported by the following statement of the eighth participant.

"Can I now say with confidence, that between me and [the centre], there is no one else that can care for my children better." Interview 8

Two other participants also reported that they know best how to look after their infant (interview 2 & 3). Participants reported that in addition to information, confidence comes over time (interview 1 & 2), although criticism and difficulty in bonding can influence confidence negatively (interview 2 & 8).

For this theme it can be concluded that parents of infants with complex health needs in a South African context do need self-confidence in the care of their infant through practical and psychological support. The analysis of this theme is provided in Figure 4-10.

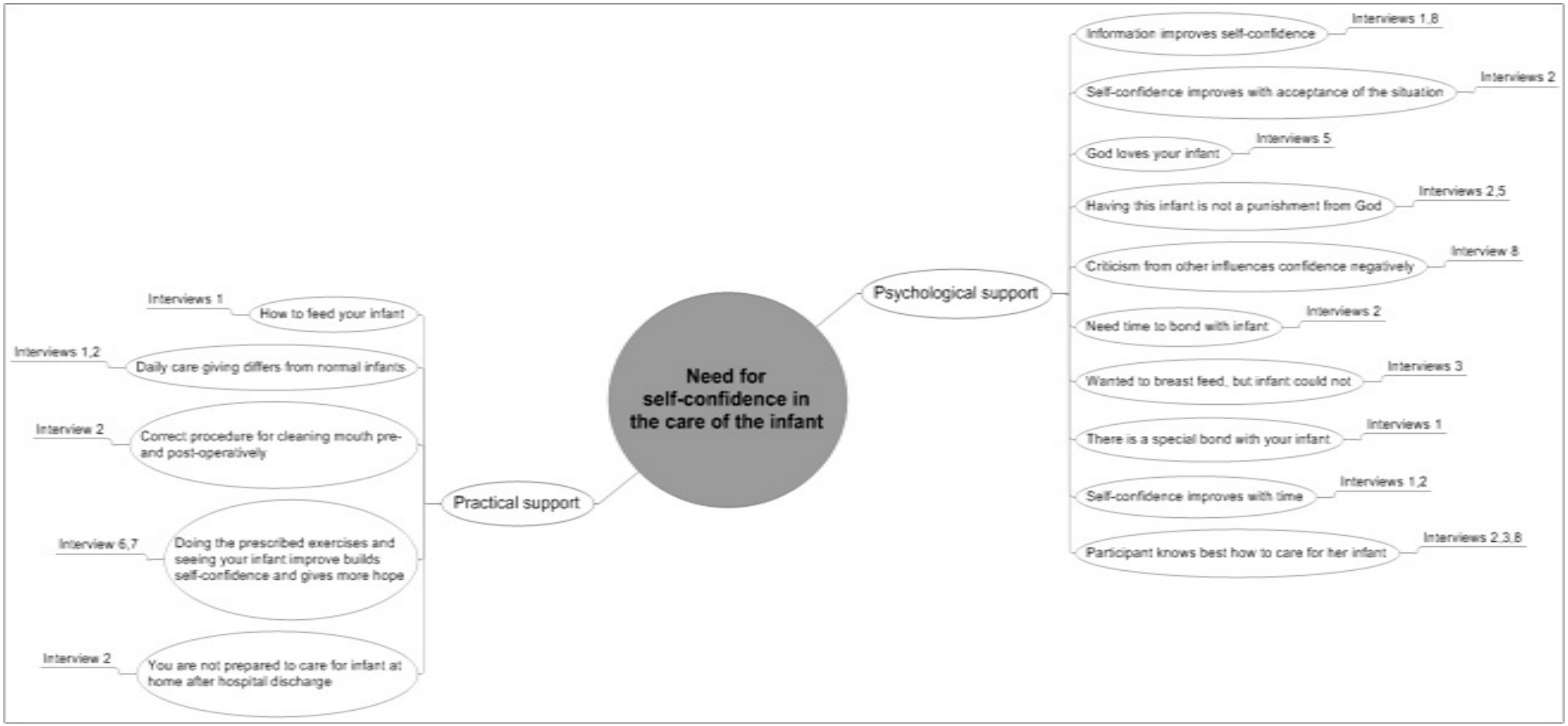

Figure 4-10: Need for self-confidence in the care of the infant

4.7.5 NEED FOR SOCIAL SUPPORT

All the participants in the interviews reported their social network to be an important support system and three of the participants expressed this as their most important need (interview 5, 7 & 8). Family members are the main providers of emotional support (interview 1 & 5) and play a big role in encouraging and motivating parents. It is also family members that help to look after the infant (interview 1, 2, 3, 4, 5, 6 & 8). This is in contrast with what the participants of Moola (1996:144) reported, namely that assistance from family members is lacking. As family members often look after the infant and support the parents, they also can become exhausted (interview 8).

Although family plays an important role in supporting the participants and caring for the infant, one participant reported that family do not always understand (interview 8) and may judge easily or become over-involved (interview 8). Tong *et al.* (2010:555) reported similar findings. The participant of the fourth interview revealed that she did not tell her family about the condition of the infant yet; further showing that family is not always the main support system. Friends may also play an important role in giving social support as reflected below in the statement of participant eight.

"I think rather friends than family. Family is sometimes too tired and they want to butt in too much. For a friend you can say: "This is how I want it to be done." My mother-in-law will say, but she has always done it this way." Interview 8

Spouses or partners have been reported to be the most important person in the social support network (interviews 1, 2, 3, 5, 6, 7 & 8), which is supported by the findings of Young *et al.* (1988:190). Even though the situation puts a lot of strain on the spousal relationship (interview 8) it was emphasised by the participants that they will not be able to cope without this person (interviews 2, 3 & 8), as expressed in the following statements.

"Yes, the dad is a very big role...then he just says: "Love, it is okay, all will be okay, she is strong, she is our baby."...he is always the pillar of strength you never had." Interview 2

"It is important that your partner should support you. Yes, because if that is not there, then I don't know how you even..." Interview 3

"It is a difficult one...And we handle it differently...I have said it to him many times: "I talk to you, not because I want to be punished, but because you are the only one who really understands what it is to live in this house.". And it is true....I cannot do without him" Interview 8

The grandmother of the infant has also been reported as an important support person to the participants (interviews 1, 2, 3 & 6).

In both components of this study the participants felt that they needed support from their larger community as well, but it was emphasised more during the interviews. Studies analysed in the integrative literature review only reported that they wanted acceptance from the public (Diehl *et al.*, 1991:172) and a community that is more informed (Moola, 1996:148). Participants of the interviews also derived much support from their colleagues (interview 2 & 8), but said this can only be done if you accept their support and confide in them (interview 2). This relates to acceptance of the situation and consequently being able to tell other people about your infant's condition and your needs. Participants found that their social support structure grew when they allowed themselves to open up to people about their infant. Participants in the interviews were not afraid of how the community will react to their infant (interview 1, 4 & 6).

Considering both parts of the study it can be concluded that parents of infants with complex health needs in a South African context need social support from their family and community. The analysis of this theme is provided in Figure 4-11.

A new theme not found in the integrative literature review, was also identified from the interviews and will be discussed in the next paragraph.

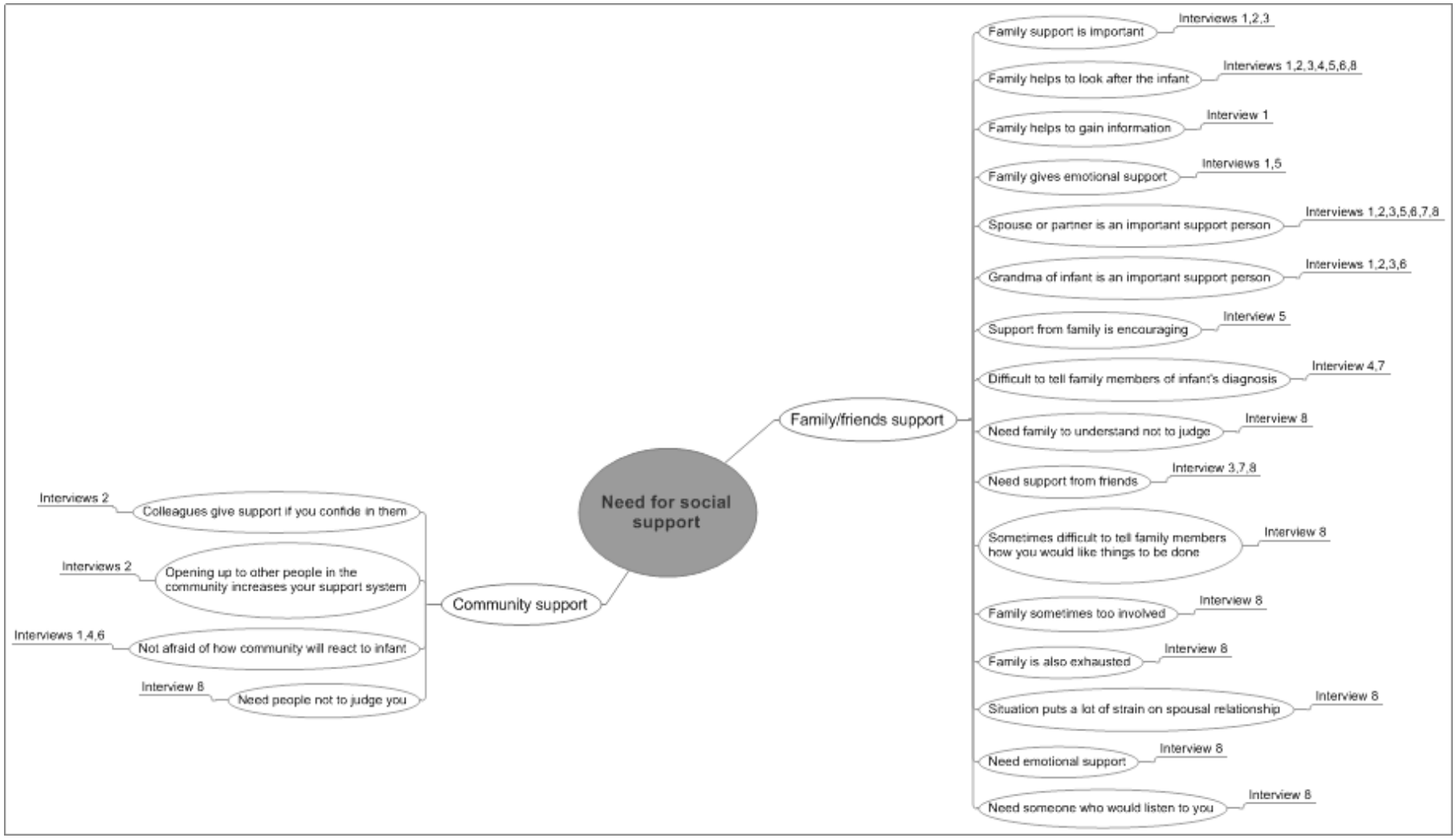

Figure 4-11: Need for social support

4.7.6 NEED FOR NORMALITY

This is a new theme identified during the interviews and relates to the participants' need for their infant to be treated and to feel normal. Although this theme was not represented in all the interviews, it was emphasised, and the third participant expressed this as her most important need, as stated below.

"Well, I think my greatest need is that he, uhm, you know, will feel like a normal child. You know, you, you will raise him by telling him there is nothing wrong with you, and sure the friends will ask questions and stuff, but you are totally normal. And you know, if we, if he can have a strong personality it will be wonderful, then..." Interview 3

The participants wanted their infants to grow up with confidence (interview 1, 2 & 3). When asked what kind of support she needed to achieve this, one participant replied that it can only come from themselves as parents (interview 3). The importance of recognising what is normal in the infant was also discussed by the participant of interview five. In the midst of the abnormalities, she chose, for example, to recognise that the infant's cry is normal like any other infant's.

Relating to this, parents needed to accept their infant and the situation first (interview 1). The need for normality is also recognised by Fisher (2001:601-602), who has done a literature review on the needs of parents with chronically sick children. Although the context of this review correlates with the context of this study, the description of the need for normality differs. Through the interviews the need for normality is more focussed on the infant and how participants hoped for the infant to feel and be treated normal, where in the review done by Fisher (2001) the focus of normality is on daily living and activities and how participants strive to make their lives still feel normal (Fisher, 2001:602).

However, the need for normality expressed by participants in the interviews does agree with how Broberg (2011:412) describes it. Broberg (2011:412) describes different positions parents took when their child was diagnosed with an intellectual disability, including the *dismissing the tragedy subject position*. Within this position the disability is described as insignificant and normality is emphasised, which is how the participants of the interviews described their need for normality (interviews 1, 2, 3, 5 & 7) and is reflected in the response of participant seven.

"Yes, sometimes I forget she's a [the condition] baby." Interview 7

This theme again also relates to the need for information (on the infant's condition, what to expect from the future, etc.) (refer to paragraph 4.7.1), the need for counselling (refer to paragraph 4.7.3.1), need for self-confidence regarding the care of the infant (refer to paragraph

4.7.4) and the need for social support (refer to paragraph 4.7.5), as parents will need these support in order to fulfil the need for normality.

It can be concluded from the interviews that the participants of this study have the need for normality. The analysis for the need for normality is provided in Figure 4-12.

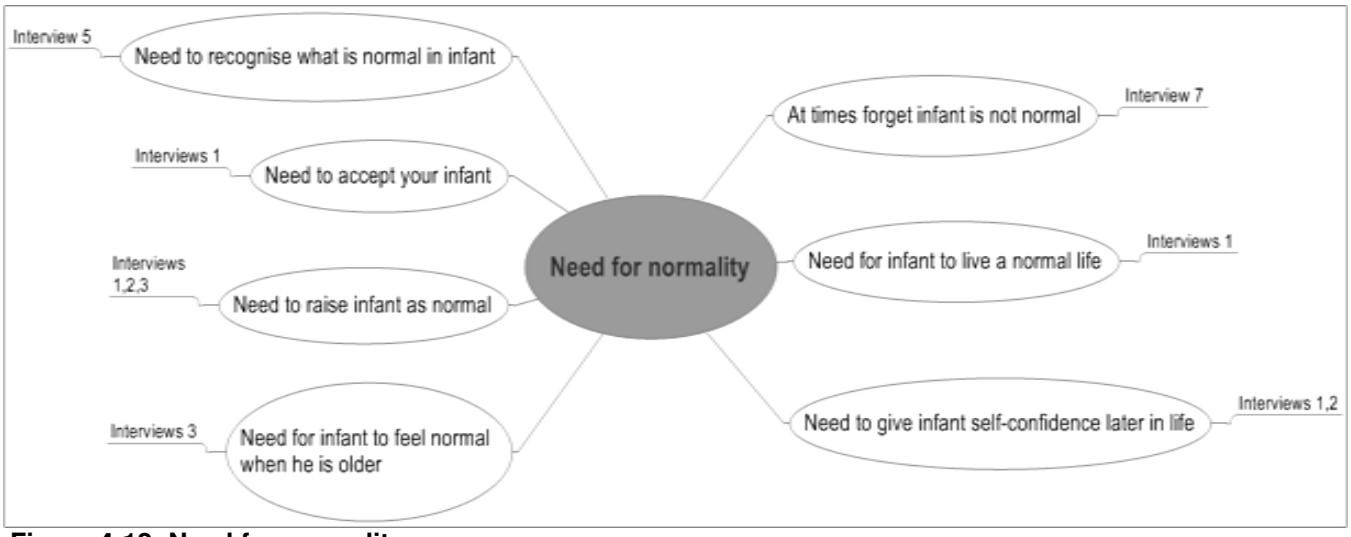

Figure 4-12: Need for normality

The objective of the interviews was to provide an emic perspective on the support needs of parents of infants with complex health needs in a South African context, informed by the findings of the integrative literature review. Table 4-3 indicates the interviews supporting the concluding statements of the integrative literature review and therefore showing the relevance in a South African context. Concluding statement 5 and 14 were not supported by the findings of the interviews.

Table 4-3: Summary of concluding statements supported by the interviews

Concluding statements from integrative literature review	Supported by interviews		
	Yes	No	Interview
Main theme: Need for information			
1. Parents need information regarding their infant's condition, care, daily routine, medication use, development and future.	√		**1 - 7**
2. Parents need information on services, resources and support available.	√		**1, 2, 3 & 8**
3. Parents need written information on the care and condition of their child to share with others.	√		**1, 2, 3 & 6**
4. Parents need accurate and up-to-date information they can understand.	√		**1 & 8**

Concluding statements from integrative literature review	Supported by interviews		
	Yes	No	Interview
5. Parents need information at an early stage from a professional.		√	
Main theme: Need for parent-to-parent support			
6. Parents need to communicate, share experiences, emotions and information with parents in a similar situation.	√		**1, 2, 3, 4, 6, 7 & 8**
7. Parent-to-parent support is the receiving, as well as giving, of support.	√		**1 - 7**
Main theme: Need for professional support			
8. Parents need to discuss their fears, anxieties and concerns with a familiar professional.	√		**1, 2, 3 & 5**
9. Parents need a service coordinator that is approachable and familiar with the family and infant.	√		**1, 2, 3, 4, 5, 6 & 8**
10. A service coordinator is a professional who assists parents in organising services, provides support, information and advice and acts as an advocate for the family.	√		**1, 2, 3, 4, 5, 6 & 8**
11. Parents need knowledgeable, accessible professionals to provide quality care.	√		**1, 2 & 8**
12. Parents need honest and approachable professionals with which to discuss their concerns and their infant's condition.	√		**2 & 8**
13. Parents have the need for quality, professional services for their child, including child care, medical care and educational services.	√		**1, 2, 3 & 8**
14. Parents have the need for financial assistance.		√	
Main theme: Need for self-confidence in the care of the infant			
15. Parents need to be confident in the care of their child, achieved through professional support, skills development and knowledge.	√		**1, 2, 3, 5, 6, 7 & 8**
Main theme: Need for social support			
16. Social support and acceptance from family, friends and the community are important to parents.	√		**1 - 8**

4.8 CONCLUSION

Eight individual face-to-face interviews were conducted. This was the second phase of the study and a contextualising component to reach the second objective of this study: The interviews were analysed according to a framework based on the findings of the integrative literature review and one new theme was identified: the need for normality. Findings from the integrative literature review and the interviews were synthesised as the second point of interface and a conclusion reached on the support needs of parents of infants with complex health needs in a South African context.

Chapter 5: Evaluation, limitations and recommendations of the study

5.1 INTRODUCTION TO THE CHAPTER

Chapter five is the final chapter of this study and evaluates the study objectives and rigour, describes the limitations of the study and the recommendations for practice, education and research.

5.2 EVALUATION OF THE STUDY

Evaluation of this study is on the achievement of the objectives as well as the rigour of the study.

5.2.1 EVALUATION OF ACHIEVEMENTS OF THE OBJECTIVES

The aim of this study, as described in chapter one, was to explore and describe the support needs of parents of infants with complex health needs in the community.

Two objectives were set to reach this aim:

- Objective 1: Critically appraise and synthesise the best available evidence on the support needs of parents of infants with complex health needs.
- Objective 2: Explore and describe parents' emic perspective on their support needs as parents of infants with complex health needs in a South African context.

5.2.1.1 Objective 1: The integrative literature review

The first objective was to explore and describe the support needs of parents of infants with complex health needs by means of an integrative literature review. The realisation of this method is described in chapter three as a five-step process. A total of 2914 documents were found during the multi-stage search, and 22 of these articles met the inclusion criteria for critical appraisal. 11 of the appraised articles were of high methodological quality and were used for data analysis and synthesis and the formulation of 16 concluding statements. The concluding statements formed the basis of the interview guide used in the interviews as the first point of interface.

5.2.1.2 Objective 2: The interviews

The second objective was again to explore and describe the support needs of parents of infants with complex health needs, but this time through interviews in order to determine the emic perspective of these parents within a South African context. Eight individual face-to-face interviews were conducted with parents of infants with complex health needs. Chapter four discussed this method and the results of the interviews. The results of the integrative literature review and interviews were synthesised as the second point of interface to form six main themes (refer to Figure 5-1) and the support needs of parents of infants with complex health needs were related to concepts of the modelling and role modelling theory of Erickson *et al.* (1983).

Figure 5-1: Main themes of integrative literature review and interviews

5.2.2 EVALUATION OF RIGOUR

The rigour of the integrative literature review in this study was evaluated on utilising systematic methods, evidence of critical appraisal, transparency and auditability.

Different techniques were used to ensure utilisation of *systematic methods* during the integrative literature review, including:

1) Performing an initial scoping search to refine the search strategy and key words for the use in the search.
2) These key words were confirmed as applicable by a librarian knowledgeable in searching databases.

3) A thorough search strategy, exhausting all available research literature on the topic available to the researcher, including grey and unpublished literature.
4) Utilising an independent reviewer who is experienced in systematic reviews during all stages of the review.
5) Specifying inclusion and exclusion criteria for the studies to be included.
6) Organising data extracted and presenting it in a table in order to compare the studies used in the review

Evidence of critical appraisal is an important criterion to ensure rigour and steps has been taken to ensure this.

1) Relevant and reliable critical appraisal instruments were utilised and the instruments were provided to the reader.
2) Studies were consistently scored and the results of the critical appraisal of each study were made available to the reader of the results (refer to Table 3-2).
3) Studies were critically appraised by two reviewers and their allocated scores showed a strong correlation.
4) The grading system were explained and grades allocated to studies were recorded (refer to paragraph 3.2.3.2) and indicated during analysis of the integrative literature review.
5) Only studies of high methodological quality were included for data analysis and synthesis.

Auditability is an important strategy to ensure rigour as it makes decisions made at each step of the integrative literature review clear. This ensures that readers can evaluate decisions made and understand how conclusions were reached. Auditability is also referred to as transparency and was ensured through keeping an audit trail by:

1) Explaining the background of this study and how the review question was formulated.
2) Recording the data sources used in the search strategy and the results of the search at each data source.
3) Keeping a clear record of the key words used at each data source.
4) Setting inclusion and exclusion criteria for the studies to be critical appraised.
5) Keeping a clear record of the review forms used for critical appraisal and the scores allocated by each reviewer to a specific study.
6) Keeping a clear record of the studies used for data analysis.
7) Explaining how thematic analysis was done and how themes were identified.
8) Development of themes based on the literature and with clear reference to the literature.
9) Supporting the concluding statements with referenced literature.
10) Keeping a clear record of the limitations of the study.

The following strategies were utilised to ensure rigour of the interviews:

1) Participants from different backgrounds and setting were recruited to be interviewed.
2) The interviews were audio-taped in order to be listened to again and also to be transcribed.
3) Field notes were taken at each interview on the setting, main areas of discussion, the atmosphere of the interview and methodological issues of the interviews. These notes were especially handy when the recording of the interview was of poor quality.
4) The same interview guide was used with all the interviews.
5) Transferability was considered and a description of the participants, the setting and context were given.
6) A co-researcher was involved with data analysis.
7) Data analysis were explained and presented visually.
8) Although data saturation was not attempted, data were still analysed for contradicting, similar and new themes.

5.3 LIMITATIONS

A number of limitations were identified during the different stages and components of the study.

5.3.1 LIMITATIONS OF THE STUDY

As a novice researcher it was challenging to utilise and combine two different methods in one study. It was not always clear how to argue the mixing of the methods, as some of the literature describing the mixed method approach was contradicting and therefore this study utilised a less common approach for data integration.

5.3.2 LIMITATIONS OF THE INTEGRATIVE LITERATURE REVIEW

There is the chance that not all available literature on the support needs of parents of infants with complex health needs was included in the search, although a comprehensive search was done from numerous data sources.

5.3.3 LIMITATIONS OF THE INTERVIEWS

As this study was part of the researcher's master's degree, she conducted the interviews herself, although she is not an expert in conducting interviews. During some interviews the researcher found it difficult to probe participants and help them to relax, which may have led to these interviews not providing rich information from the participants. The researcher found it especially difficult to conduct the interview if it was not in the first language of the participant. Richer data may be acquired if the interviews are conducted in the first language of the

participant. Further, the support needs discussed during the interviews may be restricted to the needs participants are willing to share.

Another limitation is that the interviews were only conducted with mothers of infants with complex health needs. Including fathers or conducting the interviews with couples may give a different perspective on the support needs of parents of infants with complex health needs. The interviews were conducted in one of South Africa's larger cities and therefore not in the context of rural South Africa, which may therefore not reflect the needs of parents in these areas. As only eight participants participated in the interviews the findings cannot be generalised.

Lastly, some of the interviews did not audio-record well and the researcher had to rely on her field notes to remember what was said in the interview.

5.4 RECOMMENDATIONS

From the findings of this study the following recommendations for practice, education and research can be made.

5.4.1 RECOMMENDATIONS FOR PRACTICE

1) Health care providers should keep up to date with the latest information on the condition of the infants they treat in order for them to provide parents with accurate, up-to-date information on their infant's condition and daily care. Written information should be made available to hand out to parents as this was identified as a need for some interview participants and in the literature.
2) Parents should be provided with sufficient information on services and support available and how to access them.
3) Health care providers can bring parents into contact with each other.
4) Counselling should be made available for parents after the diagnosis of their infant with complex health needs.
5) The multi-disciplinary team should allocate a service coordinator to each family with an infant with complex health care needs. The registered nurse is in an ideal position in the community setting to fulfil this role as service coordinator.
6) Health care providers should refer their clients timely and correctly. In the community setting an algorithm should be available on when, how and where to refer these patients.
7) Health care providers should educate and support the parents of infants with complex health needs in order for them to gain confidence in the care of their infant.
8) Health care providers should acknowledge the support parents derive from their social structure and involve them in order to provide better support.

9) With the shortage of health care providers in South Africa, it is important that each provider should take the responsibility for supporting the parents of infants with complex health needs they work with.

5.4.2 RECOMMENDATIONS FOR EDUCATION

1) A basic overview of the most prominent conditions and how to support parents of infants with these conditions should be included in the undergraduate curricula of nursing, as they are usually the first health care providers these parents make contact with in the community setting.
2) Community nurses should have a training program available to them on supporting parents of infants with complex health needs in the community.
3) Regarding mixed method studies, each institution must have a clear guideline on what approach or view they want their students to follow, to reduce confusion and ensure a clear format of the method.
4) It would be valuable to have a mentor, skilled in conducting interviews, available to support and teach the novice researcher in conducting interviews. This will also enhance the rigour of the studies of the novice researchers and enable them to grow professionally.

5.4.3 RECOMMENDATIONS FOR RESEARCH

1) More extensive, research is urgently needed on the support needs of parents of infants with complex health needs, specifically in the rural areas of South Africa to ensure comprehensive evidence on their support needs.
2) With regard to the support needs of parents of infants with complex health needs in the community, the role of the registered nurse should be defined and described, which in turn may lead to improved service delivery.
3) The differences in information needed on the infant's condition should be evaluated between different socio-economic groups in order to provide sufficient information.
4) How the support needs of these parents are viewed and regarded by health care providers should be explored in order to educate the providers as needed. This will also highlight barriers to support given by the health care providers.

5.5 CONCLUSION

Chapter five was the final chapter of this research study. The study was evaluated on the achievement of the objectives and rigour. All objectives were achieved and strategies to ensure rigour, in both phases of the study, were implemented. Findings of this study were concluded from the results of the two phases of the study and limitations were discussed according to these phases. This was followed by recommendations for practice, education and research.

The findings of this study described five themes identified from the integrative literature review. The need for information theme was divided into two sub-themes: types of information needed and communication. The other themes identified were the need for parent-to-parent support, the need for professional support (which included the need for counselling, a service coordinator, accessible and approachable professionals and professional services), the need for self-confidence in the care of the infant and the need for social support from family and the community. The interviews supported these findings in a South African context and described an additional theme: the need for normality.

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ADDENDUM 2-1

CRITICAL APPRAISAL INSTRUMENTS

Qualitative review form – Letts *et al*. (2007)			
Study title			
Themes	***Description***	***R1***	***R2***
STUDY PURPOSE: Was the purpose and/or research question stated clearly? yes no	Outline of the purpose of the study and/or research question.		
LITERATURE: Was relevant background literature reviewed? yes no	Describe the justification of the need for this study. Was it clear and compelling?		
	How does the study apply to your practice and/or to your research question? Is it worth continuing this review?		
STUDY DESIGN: What was the design? phenomenology ethnography grounded theory participatory action research other	Was the design appropriate for the study question? (i.e., rationale) Explain.		
Was a theoretical perspective identified? yes no	Describe the theoretical/philosophical perspective for this study e.g., researcher's perspective.		
Method(s) used: participant observation interviews document review focus groups other	Describe the method(s) used to answer the research question. Are the methods congruent with the philosophical underpinnings and purpose?		
SAMPLING: Was the process of purposeful selection described? yes no	Describe sampling methods used. Was the sampling method appropriate to the study purpose or research question?		
Was sampling done until redundancy in data was reached? yes no not addressed	Are the participants described in adequate detail? How is the sample applicable to your practice or research question? Is it worth continuing?		
Was informed consent obtained? yes no not addressed			
DATA COLLECTION: **Descriptive Clarity** Clear & complete description of site: yes no participants: yes no Role of researcher & relationship with participants: yes no Identification of assumptions and biases of researcher: yes no	Describe the context of the study. Was it sufficient for understanding of the "whole" picture? What was missing and how does that influence your understanding of the research?		
Procedural Rigour Procedural rigour was used in data collection strategies? yes no not addressed	Do the researchers provide adequate information about data collection procedures e.g., gaining access to the site, field notes, training data gatherers? Describe any flexibility in the design & data collection methods.		

DATA ANALYSES: **Analytical Rigour** Data analyses were inductive? □ yes □ no □ not addressed Findings were consistent with & reflective of data?□ yes □ no	Describe method(s) of data analysis. Were the methods appropriate? What were the findings?		
Auditability Decision trail developed? □ yes □ no □ not addressed Process of analyzing the data was described adequately?□ yes □ no □ not addressed	Describe the decisions of the researcher re: transformation of data to codes/themes. Outline the rationale given for development of themes.		
Theoretical Connections Did a meaningful picture of the phenomenon under study emerge? □yes□ no	How were concepts under study clarified & refined, and relationships made clear? Describe any conceptual frameworks that emerged.		
OVERALL RIGOUR Was there evidence of the four components of trustworthiness? Credibility □ yes □ no Transferability □ yes □ no Dependability □ yes □ no Confirmability □ yes □ no	For each of the components of trustworthiness, identify what the researcher used to ensure each. What meaning and relevance does this study have for your practice or research question?		
CONCLUSIONS & IMPLICATIONS Conclusions were appropriate given the study findings?□ yes □ no	What did the study conclude? What were the main limitations in the study?		
Comments			

Checklist for assessing the quality of quantitative studies – Kmet *et al.* (2004)				
Study Title				
Criteria	**Yes**	**Partial**	**No**	**N/A**
1 Question / objective sufficiently described?				
2 Study design evident and appropriate?				
3 Method of subject/comparison group selection or source of information/input variables described and appropriate?				
4 Subject (and comparison group, if applicable) characteristics sufficiently described?				
5 If interventional and random allocation was possible, was it described?				
6 If interventional and blinding of investigators was possible, was it reported?				
7 If interventional and blinding of subjects was possible, was it reported?				
8 Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?				
9 Sample size appropriate?				
10 Analytic methods described/justified and appropriate?				
11 Some estimate of variance is reported for the main results?				
12 Controlled for confounding?				
13 Results reported in sufficient detail?				
14 Conclusions supported by the results?				
Comments				

ADDENDUM 2-2

INFORMATION LEAFLET AND INFORMED CONSENT

Exploring the support needs of parents of infants with complex health needs in the community

Dear prospective participant,

1) Introduction

We invite you to participate in this research study. This information leaflet will help you to decide if you want to participate. Before you agree to take part you should fully understand what is involved. If you have any questions that this leaflet does not fully explain, please do not hesitate to ask the investigator, Emmaré Stronkhorst.

2) The nature and purpose of this study

The aim of this study is to gain a better understanding of the support needs of parents of infants with complex health needs in the community. As a parent of an infant with complex health needs, you are a very important source of information on the support parents need in the community (when at home).

3) Explanation of procedures to be followed

This study involves an interview of 30 minutes to one hour where I will ask you what your support needs were and still are, to better care for your baby.

If you decide to participate in this study you will be interviewed by me, Emmaré Stronkhorst, at a time and location convenient to you. The interview may last 30 minutes to one hour. The interview will be recorded with a digital voice recorder and you may ask to stop the recording at any time during the interview or that some of the information should be disregarded.

4) Risk and discomfort involved

There are no risks in participating in the study. The interview will take some of your time. If some of the questions we are going to ask you make you feel uncomfortable, you need not answer them if you don't want to. The interview will take about 30 minutes to one hour of your time.

5) Possible benefits of this study

Although you will not benefit directly from the study, the results of the study will enable us to better support parents with infants with complex health needs in future. However, at the end of the interview we will give you the opportunity to ask questions and/or advice.

6) What are your rights as a participant?

Your participation in this study is entirely voluntary. You can refuse to participate or stop at any time during the interview without giving any reason. Your withdrawal will not affect you in any way.

7) Has the study received ethical approval?

This study has received written approval from the Research Ethics Committee of the North-West University. A copy of the approval letter is available if you wish to have one.

8) Information and contact person

If you have any question about this study, please feel free to contact the primary researcher, Emmaré Stronkhorst during office hours at 083655 7014 or per e-mail at emmare.els@gmail.com.

You may also contact Emmaré's supervisors should you wish to:

Prof Christa van der Walt (supervisor): (018) 299 1729

Dr Welma Lubbe (co-supervisor): (018) 299 1898

You will be offered a copy of this form to keep.

9) Compensation

Your participation is voluntary. No compensation will be given for your participation.

10) Confidentiality

All information that you give will be kept strictly confidential. Once we have analysed the information no one will be able to identify you. Research reports and articles in scientific journals will not include any information that could identify you.

CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person asking my consent to take part in this study has told me about nature, process, risks, discomforts and benefits of the study. I have also received, read and understood the above written information (Information Leaflet and Informed Consent) regarding the study. I am aware that the results of the study, including personal details, will be anonymously processed into research reports. I am participating willingly. I have had time to ask questions and my questions and concerns have been addressed to my satisfaction and have no objection to participate in the study. I understand that there is no penalty should I wish to discontinue with the study and my withdrawal will not affect any treatment or access to health care in any way.

I have received a signed copy of this informed consent agreement.

Participant's signature: _____

Date: _____

Investigator's name (Please print): _____

Investigator's signature: _____ **Date:** _____

Witness's Name (Please print): _____

Witness's signature: _____ **Date**: _____

ADDENDUM 2-3

ETHICAL CONSENT FROM THE NORTH-WEST UNIVERSITY

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
POTCHEFSTROOMKAMPUS

Privaat sak X6001, Potchefstroom
Suid-Afrika, 2520

Tel: 018 299-1111/2222
Web: http://www.nwu.ac.za
Etiekkomitee
Tel: 018 2994237
E-pos: 10055355@nwu.ac.za

2 Augustus 2012

Aan wie dit mag aangaan

Geagte Prof./Dr./Mnr./Me.

Etiekaansoek: NWU-00030-12-S1 S.J.C. van der Walt

"Exploring support needs of parents of infants with complex health needs in the community"

Die aansoeker het bevredigend op die kommentaar van die evalueerders gereageer en etiese goedkeuring word aanbeveel.

Vriendelike groete

Prof. H.H. Vorster
Voorsitter

ADDENDUM 3-1

SEARCH RESULTS PER DATA SOURCE OF THE INTEGRATIVE LITERATURE REVIEW AND INTERVIEW TRANSCRIPTS

ADDENDUM 3-2

TABLE FOR DATA EXTRACTION OF STUDIES INCLUDED IN THE INTEGRATIVE LITERATURE REVIEW

Author, year, study design, rating and grade	Study purpose	Study population	Findings – needs identified	Conclusion	Limitations
Aytch *et al*., 2001 *Study design:* Qualitative, exploratory study using interviews and a questionnaire *Rating:* 11.5 *Grade:* I	To gain insight into the experiences of parents caring for young children with seizure disorders and what their perceived needs for information and support are.	Parents of children under 5 years with seizure disorder. 31 parents (including different races: white, African American, Latino, Native American and multiracial). Mothers age 22-45 Fathers age 24-50 Recruited from a paediatric neurology clinic at a university in south-eastern United States. Were eligible if child was on anti-epileptic medication and a seizure was observed in the past 12 months.	Need for information on the effect of seizures on child's early development and learning. Need for simple information on what to do when child has a seizure and in case of an emergency. Need for material to read and share with family and carers. Need for information and support and resources available. Need for access to medical staff to discuss child and family concerns. Need to communicate with other parents in similar situation. Sources of support were family members, close friends and members of their church.	Support and resources are essential in coping with child who has seizures.	Sample was not representative of the population.
Bailey & Simeonnssen, 1988 *Study design*: Survey *Rating*: 8 *Grading*: II	To assess the functional needs of parents with young handicapped children.	Two-parent families participating in home-based infant intervention programs. 32 families Fathers and mothers completed forms separately. Average age of infants 14 months.	Need for information on how to teach child, available services, service availability in the future, and reading material on parents who have infants similar to theirs. Information on child's condition, wanted opportunity to meet other parents, wanted more time for themselves and needed financial assistance. Concerns about the future, especially of the child.	Family needs are complex and need a comprehensive and coordinated assessment from a multidisciplinary multivariate approach.	The needs may be restricted to what the families are willing to share.

Author, year, study design, rating and grade	Study purpose	Study population	Findings – needs identified	Conclusion	Limitations
Diehl *et al.*, 1991 *Study design:* Qualitative research design with focus group interviews as research method. *Rating: 7.5* *Grade:* II	To identify the needs of parents of children with medically complex needs from their own perspective.	Caretakers of children with chronic debilitating diseases or conditions. (24h day care medical nursing and health supervision) n=80 (during nine focus group interviews) 71 females and 9 males. Care givers of Children aged 0-21 years. Done in Florida.	Need to be informed on the child's condition and trained in caring for the child. Need for quality respite care. Need for support groups and counselling. Need for information on resources (support groups) available. Need for understandable information on the child's condition. Need for information on home care and future expectations. Need for a liaison worker. Need for provision of information at the right time. Need for training on the use of equipment. Need for information on available equipment. Need for a competent case manager. Need to be assertive and informed. Need for financial assistance and information on where to find it. Need for information on medication use. Need to be included in decision-making process. Need for nutritional and feeding information for their child. Need for information on normal development of their child. Need for information on what to expect in the future. Need to be listened to and express fears and feelings (on death and dying).	In general a lack of information was experienced. Parents need centralisation of services, they feel they need to be assertive just to get services and information needed, support groups are very important to parents, information on home care was mentioned often. The quality of services was not the problem but how to access those services.	No limitations mentioned.

Author, year, study design, rating and grade	Study purpose	Study population	Findings – needs identified	Conclusion	Limitations
Kerr & McIntosh, 2000 *Study design:* Hermeneutic phenomenology using in-depth interviews (retrospectively) *Rating:* 7 *Grade:* II	To explore the impact and benefits of parent-to-parent support when a child is born with a disability. (Congenital limb disability)	Parents of children born with a disability. Maximum variation sampling. 63 parents from different geographical and socio-economic settings, with children ages ranging from a few months to 16 years with a variety of limb deficiencies. Recruited from 4 limb fitting centres in Scotland, a major hand and plastic surgery unit in west of Scotland and REACH (a national association for families of children with hand and arm deficiencies)	Need for information on what the future holds. Need for parent-to-parent support. Need to offer parent-to-parent support.	Parent-to-parent support can relief and/or buffer stress and provides opportunities for learning not derived from other sources.	No limitations reported. Poor auditability and procedural rigour.
Kirk & Glendinning, 2002 *Study design:* Qualitative research methods. Face-to-face, in-depth interviews. *Rating:* 7 *Grade:* II	Twofold: to explore the experiences of 1) parents caring for technology-dependent children at home and of 2) the health care professionals supporting them in the community.	Parents of technology-dependent children. Sample 1: Purposive sampling to include a range of technologies, patterns of community services and time the child has been cared for at home. Sample 2: Parent provided names of	Need for emotional support in the form of "being there" (an approachable and accessible someone familiar with the child circumstances), "listening and counselling" (professional to share with fears and anxieties and feelings) and "promoting self-confidence". Need for practical support through advocacy for the child or family, hands-on care and organising services and equipment. The need for provision of information on the	Parents carry out complex clinical procedures and are becoming experts that need three dimensional support, emotional support, instrumental/practical help (advice counselling) and advocacy and information from	Small sample size reported.

Author, year, study design, rating and grade	Study purpose	Study population	Findings – needs identified	Conclusion	Limitations
		professionals involved in their child's care and professionals were also purposively selected to cover a range of different professionals (nurses, doctors, social workers and teachers). Also 3 nurses planning discharge from hospital of these children and 3 health authority purchasers. n=24 children and n=44 professionals. Children 4 months to 17 years old.	child's condition, caregiving and services available. This included teaching and positive feedback	professionals.	
Konrad, 2007 *Study design:* Qualitative study with psychological phenomenological design. Open-ended interviews. *Rating:* 8 *Grade:* II	To better understand the experiences of mothers who have seriously ill or dying children in order to improve health care provision.	Mothers of seriously ill and dying children. Purposive, non-random sample, recruited through a local paediatric palliative program. n=12, children from birth to age 15.	The need for parent-to-parent support (mentorship) – for informational and emotional support. The need to be well-informed on the child's condition and caregiving needs. The need to be an advocate for your child.	Parent-to-parent support is important and seen as beneficial by mother of children who is seriously ill or dying.	Small sample size and non-random purposive sample (although this is the right technique for study design).
McPhee, 2010 *Study design:* Retrospective	To examine the perceived needs and correlates of Maine parents of premature	Maine parents who were the primary care givers of a premature infant born between 1990 and 2003.	Early intervention services for child, services and support for parents, community resources, child care and financial resources were not needed or	Medical services were desirable and the need for this increased over time. Services and	This study was based on memory and retrospection that can be

Author, year, study design, rating and grade	Study purpose	Study population	Findings – needs identified	Conclusion	Limitations
longitudinal study *Rating:* 8 *Grade:* II	infants related to the chronological distance from the NICU.	Infants must have been born prematurely before 37 weeks gestation, graduated from a Maine NICU, not live in a group home or nursing home, resided with primary caregiver at least until age 5 years. n=134 Convenience sampling of parents of premature infants born 1999-2003. Recruitment through public media advertising, agency referrals and personal contacts.	minimal needed after discharged from the NICU and the first 6 months. Medical services were perceived as important at this stage. The need for child care support for parents increased over time.	support were only minimally beneficial.	influenced by a number of things. It can be less reliable. Population was difficult to access. Sample size was small. Questionnaires were not complete.
Molinari & Freeborn, 2006 *Study design:* Grounded theory research. Interviews used as method.	To understand how families decide if they need professional services. To produce a process theory that both provides a foundation for future research and informs practice.	Families who have adopted a child or children with special needs. n=20 Recruited by word of mouth. Families were selected for diversity and included 3 single women and 17 two-parent families. Parents ages 25-59 years. Children had mental health issues and physical disorders. Children younger than 1 year to older than 24 years.	Need for information on child's condition, resources available, who to turn to, caring for the child, coping strategies and parenting. Prefer personal resources above professional ones. Need for quality and available professional services. Need for knowledgeable professionals. Need for social support. Need for financial support. Need for information on resources available.	Parents need preventative and informal supports to increase perceptions of competence.	Theory only applicable to families adopting special needs children, limited to availability of resources and limited by parents unwillingness to accept outside help.

Author, year, study design, rating and grade	Study purpose	Study population	Findings – needs identified	Conclusion	Limitations
Moola, 1996 *Study design:* Quantitative design with questionnaires as method. *Rating:* 6 *Grade:* II	To examine the life-world of Indian parents with a child with Down's syndrome.	Indian parents with a Down's syndrome child. n=20 Recruitment: Westridge Park School, Sunfield Home and Overport Down's syndrome parents' support group. Telephonically approached. No random selection due to a small population in the Durban area. Snow ball sampling done. Age of children between 0-25 years. (45% younger than 5 years).	Parents need special classes for Down's syndrome in main stream schools. Need for financial support for medical bills. Need access to professionals for information on their child's condition. Genetic counselling clinics are important in supplying counselling and information. Need for information on their child's condition (100% of parents). Prefer receiving information from knowledgeable professionals (those favouring he social worker did not have the finance to afford consultation fees elsewhere.) Need for adequate education for their child. Uncertain about their child's future (what future holds – marriage, occupation and independence). Need for information on their child's training/education prospects. Need for knowledge on their child's vocational possibilities. Need for parent-to-parent support. Use Down's Syndrome Association for help. Need assistance in raising their child (from spouses, professionals, family and community). Need for support services for parents with Down's Syndrome children. Need for sympathy from family members. Need for other people than family members	Parents were not well-informed about their child's condition and future. Half of the mothers were over 35 years and the child the first born. Having a disabled child put a lot of financial strain n the family. Parents want information from professionals. Parents need counselling and support.	Question might not have been answered truthful. Results confined to Down's Syndrome parents in an urban area. Small sample size.

Author, year, study design, rating and grade	Study purpose	Study population	Findings – needs identified	Conclusion	Limitations
			to be more informed on Down's Syndrome. Need for counselling after the birth of their baby. Need for guidance in family planning from professional, qualified peopled.		
Muggli *et al.*, 2009 *Study design:* Qualitative design utilising in-depth interviews as method. *Rate:* 8 *Grade:* II	To explore the experiences of families with a baby with Down's syndrome at the time of diagnosis and their preferences for information and support in the early time period after diagnosis.	Families with a Down's syndrome baby. n=18 Families should be fluent in English and the baby should not have been diagnosed with Down's syndrome before birth. Mother ages 25-43 years. Children 1-4 years at time of interview, born between 1 Jan 2002 and 31 Dec 2004. Recruited through the Victorian Birth Defects Register	Need for early access to parent-to-parent support. Need for updated and accurate information on child's condition. Need for a liaison worker.	Parents of newborn Down's syndrome babies expressed different levels of uncertainty and stress at the time of diagnosis and need for support from different sources emerged from the interviews.	Researcher cannot be certain that the experiences and needs of families in this study represent most families with newborn Down's syndrome babies.
Newton, 2006 *Study design:* Survey using questionnaires, with an additional qualitative component using interviews. This study used the	To service providers and policy makers on the needs of families with young children with disabilities entering the service system. To examine whether the child's age at a point of entry into the	Parents of children with developmental disabilities. T1: n=106 mothers and 70 fathers of 111 families (T1) with 74% response rate. T2: 103 mothers and 55 fathers from 103 families with 68% response rate. From this stud the 106	Mother with disabled infants had more financial needs and child care needs than mothers with older children. Need for information on how to handle child's behaviour and on child's condition and disability correlated with Parental Stress Index. (therefore these unmet needs increase parental stress) Need for support on discussing problems and solutions and need for help on	Relationship exists between child's age and mothers parenting stress.	FNS does not report on acuity of needs. And FNS is self-reporting limiting the needs to what parents can identify and willing to share.

Author, year, study design, rating and grade	Study purpose	Study population	Findings – needs identified	Conclusion	Limitations
questionnaires as data source. *Rating:* 7 *Grade:* II	service system is related to maternal parenting stress and whether there is an association between needs for support identified by mothers of children at different ages at point of entry into the service system and maternal parenting stress.	mothers from T1. Families from two Manitoba health regions who qualified for care from Children's special services. Children under 12 years of age. Basic skills in English Children with a developmental disability, not been open to programs at another time/regions Mother 19-65 years and children 5 months – 144 months.	responding to family and neighbours also correlated with PSI. No significant differences were found on the number of unmet needs between different age groups of children. All mother experienced a level of parental stress.		
Pelchat *et al*., 2004 *Study design:* Emerged from quasi-experimental research. Longitudinal study using questionnaires to evaluate an interventional program. *Rating:* 8 *Grade:* II	To evaluate the satisfaction of parents with the PRIFAM program (an interventional program for parents of infants born with a disability) in assisting them to adapt to their child's problem. (Cleft lip/palate or Down's syndrome)	Parents utilising the PRIFAM program. 47 sets of parents (n = 94) who had been through the PRIFAM program and 53 couples (n=106) were included in the comparison group were given questionnaires, with 80% response rate (n=72). Infants about 6 months of age. In Canada.	The need to have the opportunity to express their fear and worries. The need for clear and accurate information on the child's condition (especially in the first few months). Need for information on services and support available. The need for written material on the child's condition and care.	The PRIFAM program was effective in providing parental support in the family subsystems evaluated. Written information with discussion with the nurse provides reliable information leading to the success of the program.	Wording of the questionnaire may be confusing. Some of the questions may be irrelevant, considering the age of the child at the time of the questionnaire.

Author, year, study design, rating and grade	Study purpose	Study population	Findings – needs identified	Conclusion	Limitations
Tong *et al.*, 2010 *Study design:* Qualitative study utilising in-depth interviews. *Rating:* 9 *Grade:* I	To explore how chronic kidney disease (CKD) in children affect parental care givers during all stages of CKD.	Parents of children with CKD. n=20 Participants were English speaking, over 18 years of age and parents of children who were diagnosed with CKD, undergoing haemodialysis or peritoneal dialysis or who received a kidney transplant. Purposive sampling to include parents of children with all stages of CKD and minority ethnic groups. Children 0-18 years. Recruited through The Children's Hospital at Westmead and Sydney Children's Hospital.	Need for understanding and support from family. Need for parent-to-parent contact. Need for information on the child's condition, prognosis and caring. Need for written information.	Parents of children with CKD report this as being a negative experience and it appears that additional support structures and information is necessary to help these parents cope.	Transferability of findings uncertain. Non-English speaking participants not included in study. Only one interview was conducted comparison of dynamics between interviews or when both parents are together could not be done. Although the study highlights parent perspectives of service delivery, parental perspectives can differ from professional perspectives and experiences during a clinical examination
Young *et al.*, 1988 *Study design:* Qualitative study utilising interviews.	1) To assess the needs of families of infants who were discharge home on	Target group were infants discharged home on oxygen therapy between 1977 and 1984 in Southern Alberta, Canada.	Need for information on the duration of expected oxygen therapy. Need to know how to handle emergencies. Fear for SIDS Concerns on infant health, weight gain and	Need for improved access to information about care and development of infant and needs included	Small sample could not accommodate the potential effects of different interview methods.

Author, year, study design, rating and grade	Study purpose	Study population	Findings – needs identified	Conclusion	Limitations
(Retrospective) *Rating:* 7.5 *Grade*:II	continuous oxygen therapy 2) Perceptions of health professionals on the needs of these families	Identified through the Perinatal follow-up program at Alberta Children's hospital. N=65 and n=21 excluded. 44 families interviewed of 48 infants. Mostly Caucasians in stable relationships. 22 professionals.	mobility of oxygen equipment. Need for special preparations at home before infant discharge – monitoring infant, giving therapy, preparing room, obtaining equipment. Valued support of respiratory technologists. Disappointed with lack of knowledge form community nurses. Believed community resources were inadequate. Need for qualified baby-sitting services. Some expressed the need for parent-to-parent support. Spousal support most helpful. Professionals: inadequate information given, families need more information, need improved service coordination, need additional training in development of infant, need for relief services, need for recreational therapist.	social support and for qualified baby-sitters.	Reliability and validity of interview tools not evaluated. Responses could be biased. Retrospective information given.

ADDENDUM 4-1

EXAMPLE OF FIELD NOTES

Observational notes

3 April 2012, 11h00.

At participant's home in the dining room. Participant is living with her parents. House is very neat. No toys, pram etc. in the living area.

We sat directly across each other at the dining table. Radio playing in the background.

Areas of discussion: need for information on child's condition, needed more knowledgeable professionals when infant was born, struggles with medical aid, needed information on services available, the value of her service coordinator, feeding of the infant.

Theoretical

Participant appears very nervous – may be because she is so young or because of the recording.

She does not relax more as the interview progresses – as if she is afraid to give the "wrong" answer. Although, she does speak with confidence about her situation and the infant – she describes a special bond with the infant.

The participant shared more information after the interview was concluded – it may be that she was more relaxed, because the interview was now over. May also be because the recording was stopped and therefore she felt more at ease.

Methodological

First spoke to participant in general before starting the interview. The voice recording was started as the interview began. - Rather start the voice recording during the general conversation, so that the participant is not so aware of the recording, which may help her to relax.

The participant shared more information after the interview was concluded. This part of the discussion was not recorded. – May be a good idea to still keep recording after the interview for in case the participant shares more information.

Avoid asking leading questions, rather just probe the participant.