

School of Health Sciences

STUDY TITLE:

**RESTITUTION, CHAOS AND QUEST: EXPERIENCES OF FAMILIES
WITH CHILDREN DIAGNOSED WITH CEREBRAL PALSY**

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BSc, MSc

**A thesis submitted to the University of Nottingham for the degree
of Doctor of Philosophy (Ph.D.)**

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Dedication

This thesis is dedicated to my Dad and Mum who never gave up on finding ways and means to support my education from childhood to University level. I also dedicate it to my wife, Mrs. Dorothy Asante and little baby boy, Lemuel Asante, who went through all the hustles and bustles of a Ph.D. life with me.

Originality statement

Declaration: This thesis is the original work of the author and has not been submitted for any other degree or award at this or any other University

Signed..... (Emmanuel Asante) Date:

ABSTRACT

Background: Cerebral palsy (CP) is considered a major physical disability among the childhood developmental disabilities, affecting the functional development of children (Jones et al., 2007), with a prevalence of 2 to 2.5 per 1000 live births (Dolk et al., 2006, Hutton and Pharoah, 2006). Existing research is dominated by the voice of the mother with the voices of other significant family members rarely reported. Incorporation of the voices of other family members is important for a holistic understanding of the experience of living with a child with cerebral palsy. This is particularly true in developing settings, like Ghana, where it is common for both the nuclear and the extended family to live together.

Aim: This study aimed to explore the experiences of families with children diagnosed with cerebral palsy.

Epistemology, methodology, and methods: This study explored the experiences of living with a child with cerebral palsy in the family by using pragmatism as its epistemology, generic qualitative study as its methodology and Frank's illness narratives (Frank, 1995) as its explanatory framework to enhance the interpretation and understanding of the study findings. Although findings largely portrayed Frank's original typologies written in 1995, updates on his 1998 and 2013 works (Frank, 2013, Frank, 1998) were also reflected in the current study. The study recruited 30 family members through the use of purposeful sampling. Semi-structured interviews were used to collect data with each interview lasting between 60 and 120 minutes. Data was analysed using narrative thematic analysis. Ethical approval for this study was obtained from both the University of Nottingham and the Komfo Anokye Teaching Hospital. To ensure rigour, a reflexive account of the study was also taken into consideration.

Findings: The experiences of family members were represented or expressed in Frank's narratives of restitution, chaos, and quest. In the restitution narrative, family members hoped for a cure through either biomedical and/or alternative models of treatment. This was followed by intransitive restitution where they expected the children's condition to eventually heal, and transcendent restitution where they hoped for a cure from God. In the chaos narrative, family members expressed the sociocultural effects and personal impact of living with a child with cerebral palsy that led to a loss of control of the children's condition and many different aspects of their lives. In the quest narrative, family members appeared to have made sense of living with a child with cerebral palsy and constructed the *auto-mythology* and *manifesto* forms of quest. Through auto-mythology, they used romanticism to make the illness experience appear better than it seemed, through the use of meanings such as "will of God" and test from God". In manifesto, they seized on the children's condition as a means to call for social change.

Conclusion: Findings from the current study have provided new theoretical insight into the experiences of having a child with cerebral palsy in the family. The use of Frank's narrative types (Frank, 1995) have provided a novel, holistic, and a more comprehensive understanding of familial experiences of living with a child with cerebral palsy. Addition of the transcendent and intransitive sub-types of restitution, has also extended Frank's narratives. The study highlights the need of health professionals to use the narrative types of restitution, chaos, and quest as listening tools in order to address the narrative types that family members living with children diagnosed with cerebral palsy may present and to also provide adequate support.

TABLE OF CONTENTS

Dedication	i
Originality statement.....	ii
ABSTRACT	iii
TABLE OF CONTENTS	iv
ACKNOWLEDGEMENTS	x
SCHOLARLY OUTPUTS	xii
Conference Presentations and posters	xii
Scholarships and Awards.....	xii
LIST OF TABLES.....	xii
LIST OF FIGURES.....	xiii
LIST OF APPENDICES.....	xiv
ABBREVIATIONS AND ACRONYMS	xv
GLOSSARY	xviii
CHAPTER ONE: INTRODUCTION.....	21
1.1 THE RESEARCH CONTEXT: GHANA	21
1.1.1 Geography	21
1.1.2 History	22
1.1.3 Economy	23
1.1.4 Demographic Profile.....	24
1.1.5 The healthcare system in Ghana.....	25
1.1.6 Religion in Ghana.....	28
1.1.8 Housing arrangement in Ghana	30
1.1.9 Family structure, formation and family life in Ghana.....	31
1.1.10. Children with disabilities in the Ghanaian family.....	32
1.1.11.Disability theory within Ghana’s context	33
1.1.11.1 The medical model within Ghana’s context	33
1.1.11.2 The structural model within Ghana’s context.....	34
1.1.11.3 The cultural model within Ghana’s context.....	35
1.1.12 Cerebral palsy related theories.....	36
1.1.12.1 Symbolic Interactionism	36
1.1.12. 2 The chronic sorrow theory	36

1.1.12.3 Paterson and Zderad's humanistic theory	37
1.2 The research condition: cerebral palsy.....	37
1.2.1 Classification	38
1.2.2 Aetiology and epidemiology	39
1.2.3 Management	40
1.2.4 The chronic disease burden in Ghana: a justification for the study	41
1.3 Reflexivity: researcher position	42
1.4 Thesis Structure	44
CHAPTER TWO: LITERATURE REVIEW	45
2.1 SYSTEMISED APPROACH TO LITERATURE REVIEW	45
2.2 Aim of the review.....	45
2.3 Objectives of the review	46
2.4 Search strategy	46
2.5 Inclusion and exclusion criteria.....	47
2.6 Method	47
2.7 Results	47
2.8 Summary of the study settings	49
2.9 Critical appraisal of included studies	49
2.9.1 Scope and purpose of studies	56
2.9.2 Design	57
2.9.3 Sampling strategy.....	57
2.9.4 Analysis	58
2.9.5 Interpretation of findings.....	59
2.9.6 Researcher reflexivity	59
2.9.7 Ethical dimension	59
2.9.8 Relevance and transferability	60
2.10 Thematic synthesis of findings from various studies	60
2.11 Themes	61
2.11.1 Emotional distress	62
2.11.2 Change in family orientation and priorities	63
2.11.3 Trust and mistrust in healthcare professionals	64
2.11.4 Negative societal attitudes	65
2.11.5 Need for family support	66
2.12 Insights and gaps from the existing literature	67
2.13 Relevance and scope of the proposed study	68

2.14 Research question	68
2.14.1 Objectives	68
2.15. Conclusion	69
CHAPTER THREE: EPISTEMOLOGY, THEORETICAL FRAMEWORK AND METHODOLOGY	70
3.1 Introduction	70
3.2 Research approach: qualitative study	70
3.3 Overview of research questions and objectives	71
3.4 Epistemology, methodology and methods.....	72
3.5 Epistemology: pragmatism	72
3.6 The adopted theoretical framework: Frank's illness narrative typologies	81
3.6.1 The restitution narrative.....	82
3.6.2 The chaos narrative.....	83
3.6.3 The quest narrative	84
3.7 Methodology: generic qualitative methodology	85
3.8 Methods	87
3.8.1 The research context /study setting.....	87
3.8.2 Ethical considerations	87
3.8.3 Sampling strategy.....	90
3.8.4 Inclusion criteria	91
3.8.5 Exclusion criteria	91
3.8.6 Recruitment process	92
3.8.7 Data collection method: semi-structured interviews	92
3.8.8 Conduction of interviews	94
3.8.9 Data analysis.....	95
3.8.9.1 The thematic analysis process	95
3.8.9.2 Narrative thematic analysis	100
3.9 Establishing rigour.....	102
3.10 Reflexivity: Epistemological and methodological positioning.....	103
3.10.1 Positional reflexivity: insider and outsider status	104
3.10.1.1The insider status	106
3.10.1.2 The outsider status.....	107
3.10.2 Reflections on data collection.....	108
3.11 Conclusion	110
CHAPTER FOUR: PARTICIPANT CONTEXTS AND DEMOGRAPHICS.....	111

4.1 Introduction	111
4.2 The participants.....	113
4.2.1 Family 1.....	114
4.2.2 Family 2.....	115
4.2.3 Family 3.....	115
4.2.4 Family 4.....	116
4.2.5 Family 5.....	117
4.2.6 Family 6.....	118
4.2.7 Family 7.....	119
4.2.8 Family 8.....	120
4.2.9 Family 9.....	121
4.2.10 Family 10.....	122
4.3 Conclusion	122
CHAPTER FIVE: THE RESTITUTION NARRATIVE.....	123
5.1 Introduction to study findings.....	123
5.2 Summary of how the narratives occurred in the study findings	123
5.3 The restitution narrative.....	125
5.3.1 Introduction	125
5.3.2 Help-seeking behaviour and the restitution narrative	126
5.3.3 Hope for cure and the restitution narrative	140
5.3.3.1 Intransitive hope for cure.....	140
5.3.3.2 Transcendent hope for cure	142
5.4 Conclusion	145
CHAPTER SIX: THE CHAOS NARRATIVE	146
6.1: Introduction to the theme.....	146
6.2 Chaos.....	146
6.2.1 Loss of control	147
6.2.1.2 Cultural beliefs and perceptions about cerebral palsy and the loss of control	152
6.2.1.3 Stigmatisation and the loss of control.....	157
6.2.1.4 Personal impact of cerebral palsy	164
6.3 Conclusion	174
CHAPTER SEVEN: THE QUEST NARRATIVE	175
7.1 Introduction to findings	175
7.2 Making sense of having a child with cerebral palsy: the quest auto-mythology	176

7.2.1 Introduction to the theme.....	176
7.2.2 Cerebral palsy is the will of God.....	177
7.2.3 Cerebral palsy is a test from God.....	184
7.3 The want for societal change: the quest manifesto.....	187
7.4 Reflexivity: data analysis and interpretation.....	194
7.5 Conclusion.....	195
CHAPTER EIGHT: CRITICAL SYNTHESIS OF STUDY FINDINGS.....	196
8.1 Introduction.....	196
8.2 The kaleidoscope effect of narrative movements, narrative dominance and narrative timelines in this study.....	197
8.3 Restitution.....	199
8.4 Chaos.....	201
8.5 Quest.....	204
8.5.1 The auto-mythology.....	205
8.5.2 The manifesto.....	206
8.6 Conclusion.....	207
CHAPTER NINE: DISCUSSIONS AND CONCLUSIONS.....	208
9.1 Introduction.....	208
9.2 Frank's Illness Narratives.....	209
9.3 Existing literature on Frank's narratives.....	210
9.4 Restitution.....	213
9.5 Chaos.....	219
9.6 Quest.....	233
9.7 Implications for clinical practice.....	238
9.8 Social and policy implications.....	239
9.9 Recommendations for further research.....	241
9.10 Strengths and limitations of the study.....	242
9.10.1 Limitations.....	242
9.10.2 Strengths.....	243
9.11 Reflexivity: The effect of the research on the researcher.....	244
9.12 CONCLUSIONS.....	247
APPENDICES.....	266
Appendix 1: Ethical approval letter from study site.....	266
Appendix 2: Consent Form.....	267
Appendix 3: Participant Information Sheet.....	269

Appendix 4: Information sheet for Physiotherapists	273
Appendix 5: Study Poster	275
Appendix 6: Interview guide	275
Appendix 7: Email message from Translation Services, Ghana.....	278
Appendix 8: Existing literature on Frank's narrative typologies	279

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Asante, E., Lymn, J., Diver, C., (2016): “Experiences of family members diagnosed with children with cerebral palsy” Faculty Post Graduate Research Forum (Pharmacy and Health Sciences). The University of Nottingham, Nottingham, UK

Asante, E., Lymn, J., Diver, C., (2016): “Experiences of family members diagnosed with children with cerebral palsy”. 2 Minutes Research Impact Research Seminar, Faculty of Health Sciences, The University of Nottingham, UK

Scholarships and Awards

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Churches Together in Britain and Ireland Award for Research Students (£1000)

LIST OF TABLES

Table 1: Religious Affiliations in Ghana

Table 2: A comparison of the Traditional and SCPE cerebral palsy classification systems (Mutch et. al 1992 (Mutch et al., 1992), SCPE 2000(2000)

Table 3: the incidence of cerebral palsy in Ghana as compared to the UK (Cerebral Palsy Africa, 2014)

Table 4: Inclusion and Exclusion criteria

Table 5: results from the search database

Table 6: Quality Assessment Table

Table 7: Thematic synthesis of relevant studies

Table 8: Tenets of pragmatism applied in the study

Table 9: Participant demographic

Table 10: Demonstration of Frank's narrative types with examples from data

LIST OF FIGURES

- Fig. 1: The map of Ghana showing borders, regions, cities and major towns
- Fig.2: The population pyramid of Ghana, 2019
- Fig.3: illustration of the healthcare system in Ghana (Aseweh Abor et al., 2008)
- Fig.4: Literature Search Strategy
- Fig. 5: Flowchart for the literature search process
- Fig.6: flowchart showing safeguarding steps
- Fig.7: Maximum versus minimum participants per family
- Fig. 8: The thematic analysis process, Braun and Clarke (2012)
- Fig. 9: A diagram showing the restitution narrative, themes and sub-themes
- Fig. 10: A diagram showing the chaos narrative, themes and sub-themes
- Fig. 11: A diagram showing the quest narrative, themes and sub-themes
- Fig 12: Narrative turns and movement

LIST OF APPENDICES

Appendix 1: Ethical Approval

Appendix 2: Informed consent

Appendix 3: Information sheet

Appendix 4: information for physiotherapist

Appendix 5: Study Poster

Appendix 6: Interview guide

Appendix 7: Email Message from Translation Services

Appendix 8: Existing literature on Frank's narrative typologies

ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
AM	Alternative Medicine
BOG	Bank of Ghana
CAQDAS	Computer-Assisted Qualitative Data Analysis Software
CFS/ME	Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis
CFS	Chronic Fatigue Syndrome
COPD	Chronic Obstructive Pulmonary Disease
CP	Cerebral palsy
CPA	Cerebral Palsy Africa
DTAM	Department of Traditional and Alternative Medicine
FH	Faith-based Healers
FMHS REC	Faculty of Medicine and Health Sciences Research Ethics Committee
FMS	Fibromyalgia Syndrome
GDP	Gross Domestic Product
GETFUND	Ghana Education Trust Fund
GHS	Ghana Health Service
GHSP	Government Hospitals
GMFCS	Gross Motor Function Classification System
GNA	Ghana News Agency
GSS	Ghana Statistical Service
HCS	Health Centres

HIV	Human Immunodeficiency Virus
KATH	Komfo Anokye Teaching Hospital
LBP	Low Back Pain
LEAP	Livelihood Empowerment against Poverty
MBP	Mission-Based Providers
MDAs	Ministries, Departments and Agencies
MOH	Ministry of Health
NGO	Non-Governmental Organisation
NHIS	National Health Insurance Scheme
PCs	Polyclinics
PHC	Population and Housing Census
PhD	Doctor of Philosophy
PHMHB	Private Hospitals and Maternity Homes Board
PMDP	Private Medical and Dental Practitioners
PPC	Population, Phenomenon of Interest and Context
PWDs	Persons with Disabilities
QGIH	Quasi Government Institution Hospitals
QO	Quality of Life
SCPE	Surveillance of Cerebral Palsy in Europe
THB	Teaching Hospital Boards
THOSP	Teaching Hospitals
TMPs	Traditional Medical Providers

WHO	World Health Organisation
WHOQOL	World Health Organisation Quality of life

GLOSSARY

Terms	Definition
Belief	Conviction in the truth or existence of something that is not susceptible to rigorous proof
Cerebral palsy	A group of lifelong conditions that affect movement and coordination caused by a problem with the brain that may occur before, during or soon after birth.
Demographic characteristics	The quantifiable characteristics of a given population
Diagnosis	Identification of the nature of an illness or other problems through an examination of the symptoms
Experience	The Knowledge or mastery of a phenomenon, event or subject through involvement in or being exposed to it
Family	A group of people related through blood or marriage. A family could also refer to a unit of interacting personalities
Frank's Narrative Typologies	Illness narrative types used as "listening tools" to understand and give an interpretation to an illness experience
Help-seeking behavior	The recognition of a health concern and engaging in a range of actions to find help
Heterogeneous	Diverse in character and/ or content
Illness narratives	ways that persons affected by an illness tell their stories and makes sense of their illness or experiences, give indications of how they want their stories to be interpreted and the identification of the common cultural frameworks that are used by participants in constructing their experiences
Intransitive belief	A belief directed towards no particular object
Loss of control	Having no power or influence over the occurrence of a condition or an event

Narrative	An account of a series of related experiences or events usually with a beginning, a middle and an end
The onset of illness or condition	The beginning of illness or condition
Pre-diagnosis	The period before diagnosis
Reflexivity	Systematically attending to the context and construction of knowledge by the researcher.
Results triangulation	The act of pulling together the findings of a study with the focus of identifying similarities, differences, complexities and nuances
Romanticise	Dealing with or describing an experience or an event in an idealistic or unrealistic fashion, making it seem better or more appealing than it actually is
Stigma	A view of life, a set of personal and social constructs that usually label a person with a mark of disgrace, which sets apart them from others
Transcendent belief	A belief which is beyond the range of physical human experience

Caring for children with chronic conditions as well as their families is an embryonic field. Now is the time to seize the opportunities and move forward with research which will benefit children and their families (Bluebond-Lagner et al.,2017)



CHAPTER ONE: INTRODUCTION

1.1 THE RESEARCH CONTEXT: GHANA

1.1.1 Geography

Ghana, officially known as the Republic of Ghana is a sovereign unitary presidential constitutional Democracy in West Africa. The country spans a landmass of 238,535 km². It is bordered in the West by Cote D'Ivoire, in the north by Burkina Faso, in the east by Togo and in the South by the northeasternmost part of the tropical Atlantic Ocean, the Gulf of Guinea (Jackson, 2015). The Gulf of Guinea lies to the south and stretches across the 560-kilometre coastline. Figure 1 portrays the map of Ghana showing the borders of the country, regions, cities and major towns.

Fig 1: The map of Ghana showing borders, regions, cities and major towns



The diverse geography and ecology of Ghana range from coastal savannahs to tropical jungles. Ghana is a lowland country except for a range of highlands on the eastern border. The highest elevation is Mt. Afadjato, 884 metres above sea level, found in the Akuapem-Togo ranges, west of the Volta River. Ghana can be divided into three ecological zones: the low sandy coastal plains, with several rivers and streams; the middle and western parts of the country, characterised by a heavy canopy of semi-deciduous rainforests, with many streams and rivers; and a northern savannah, which is drained by the Black and White Volta Rivers. The Volta Lake, created by the hydroelectric dam in the East, is one of the largest artificial lakes in the world.

Ghana has a tropical climate with temperatures and rainfall patterns that vary per distance from the coastal elevation. The eastern coastal area is comparatively dry, the south-western corner is hot and humid, and the north of the country is hot and dry. The average annual temperature is about 26°C (79°F). There are two distinct rainy seasons in the southern and middle parts of the country, from April to June and September to November. The North is, however, characterised by one rainfall season that begins in May, peaks in August, and lasts until September. Annual rainfall ranges from about 1,015 millimetres (40 inches) in the North to about 2,030 millimetres (80 inches) in the Southwest. The harmattan, a dry dusty desert wind, blows from the northeast and covers much of the country between December and March, lowering the humidity and visibility, and creates very warm days and cool nights in the North. In the South, the effects of the harmattan are felt mainly in January

1.1.2 History

Ghana gained independence from British colonial rule on 6 March 1957 and became a republic in the British Commonwealth of Nations on 1 July 1960 with Accra as its administrative and political capital. Ghana operates a multi-party democracy with an executive president who is elected for a term of four years with a maximum of two terms. There is a parliament elected every four years, an independent judiciary, and a vibrant media.

There are ten administrative regions in Ghana: Western, Central, Greater Accra, Volta, Eastern, Ashanti, Brong Ahafo, Northern, Upper East, and Upper West. Upper East is the least populated region, accounting for 2% of the total population of Ghana. It was

reported by the Ghana statistical services (GSS) in 2014, that the regions have been subdivided into 216 districts to ensure equitable resource allocation and efficient administration at the local level (Ghana Statistical Service, 2014).

The Ghanaian population is made up of several ethnic groups, with the Akans constituting the largest group (48%), followed by the Mole-Dagbani (17%), Ewe (14%), Ga-Dangme (7%), and others (Ghana Statistical Service, 2014)

1.1.3 Economy

The growing economic prosperity and its democratic political system have made Ghana one of the most powerful countries in West Africa (Jackson, 2015). The structure of the Ghanaian economy has seen minimal changes over the past two decades. The agricultural sector, previously the largest contributor to the Ghanaian economy, has been overtaken by the service and industry sectors. By 2014, the service sector was the fastest-growing sector of the economy, contributing 52% of the gross domestic product (GDP), followed by the industry sector, at 27%, and the agricultural sector, at 22%. In 2014, According to the Ghana Statistical Service, (GSS), the service sector recorded its highest growth of 6%, followed by the agricultural sector with 5% growth, and the industry sector with 1% growth (Ghana Statistical Service, 2014). Overall, the 2014 real annual GDP grew by 4% compared with 7% growth recorded in 2013 (Ghana Statistical Service, 2014). About 45% of the economically active population is engaged in agriculture, and 41% provide services. A high proportion of the employed population of Ghana works in the informal sector, the majority being self-employed (Ghana Statistical Service, 2014). The leading export commodities of Ghana are cocoa, gold, and timber. Recently, the economy has diversified to the export of non-traditional commodities such as pineapples, bananas, yams, and cashew nuts. The tourism industry contributes substantially to the country's economy, as a key driver of economic growth. According to a report from the Bank of Ghana (BOG), the tourism industry is currently the third-largest foreign exchange earner after merchandise exports and remittances from abroad and has become one of the most important and fastest-growing sectors of the Ghanaian economy (Bank Of Ghana, 2007).

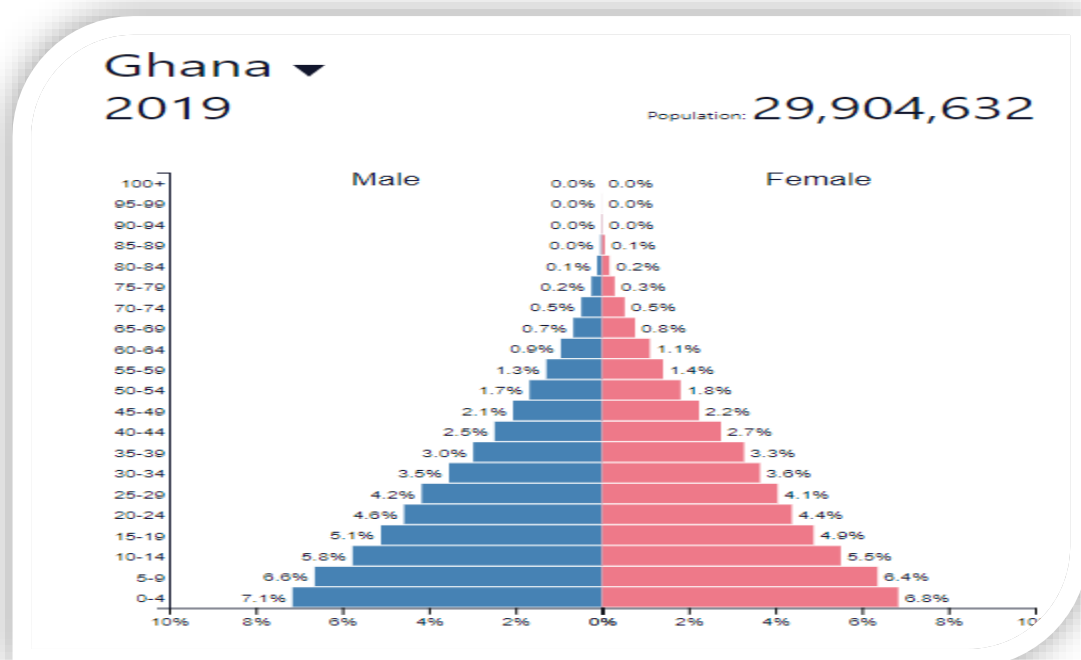
Over the past decade, the government of Ghana has embarked on various economic and poverty reduction programmes designed to improve the living conditions of its citizenry. The Livelihood Empowerment against Poverty (LEAP) programme was introduced in 2007 and, in 2008, the poor began to receive cash support monthly (Bank Of Ghana, 2007). Many changes have occurred in the education sector over the past 15 years. Pre-school education has officially been incorporated into basic education as a part of primary and junior high school. All primary schools are required to have nurseries or kindergartens. In the 2005-2006 academic year, the government absorbed school fees for all pupils enrolled in basic public schools, resulting in free education (Darko et al. 2009). During the same period, a school feeding programme was introduced on a pilot basis and has since been extended to all basic schools. While the programme aims at improving the nutritional status of school pupils, a secondary effect has been to increase enrolment. At the secondary level, the senior high school was introduced in the 2007-2008 academic year, expanding the system from three to four years, but this policy was reversed in 2009. The introduction of the Ghana Education Trust Fund (GETFUND), a public trust set up by an Act of Parliament in the year 2000, has brought many improvements to the education system. The fund provides educational infrastructure such as buildings to support the country's tertiary institutions and, thus, has improved teaching and learning within these institutions.

1.1.4 Demographic Profile

Sources of demographic information about the Ghanaian population include censuses, surveys, and administrative data (Ghana Statistical Service, 2014). Population censuses provide more comprehensive demographic information than other sources. Ghana has completed five censuses since gaining independence in 1957. The first one was conducted in 1960 and reported a population of 6.7 million. The 1970 census recorded 8.6 million people, and the 1984 census, 12.3 million (Ghana Statistical Service, 2014). In 2000, the Population and Housing Census (PHC) recorded 18.9 million, while in the 2010 PHC, 24.7 million were recorded (Ghana Statistical Service, 2014). The average annual growth rate between 2000 and 2010 was 2.5 %. The growth rates over individual periods were 2.4 %, 2.6 %, 2.7 %, and 2.5 % during 1960-1970, 1970-1984, 1984-2000, and 2000-2010, respectively (Ghana Statistical Service, 2014) The population density has increased over the years from 29 persons per square kilometre (persons/km²) in 1960 to 103 persons/km² in 2010.

The proportion of the population living in urban areas has more than doubled in the last five decades, expanding from 23 % in 1960 to 51 % in 2010 (Ghana Statistical Service, 2014). The sex ratio of 102.2 males per 100 females recorded in 1960 has declined to 95.2 males per 100 females in 2010. The proportion of the population under age 15 has also decreased from 45 % in 1960 to 38 % in 2010, while the proportion of the population aged 65 years and older increased from 3 % to 5 % over the same period (Ghana Statistical Service, 2014). Over the last five decades, life expectancy at birth has increased from 38 years to 60 years among males and from 43 years to 63 years among females (Ghana Statistical Service, 2014) Currently, the population of Ghana in 2019, stands at 29,904, 632. Figure 2. Shows the population pyramid of Ghana, which is typical of a developing country, with a broad base which is indicative of a high population growth rate.

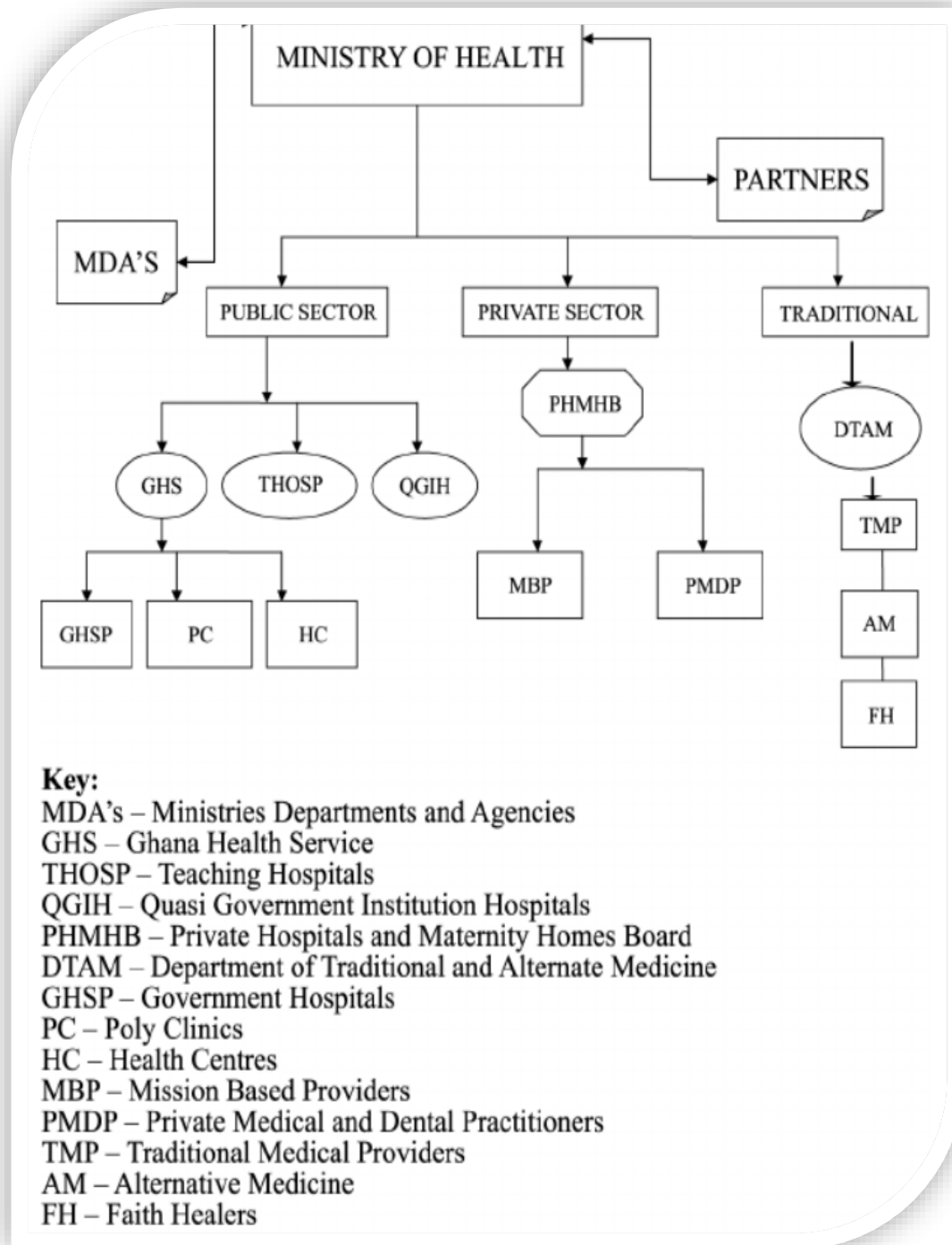
Fig 2: The population pyramid of Ghana, 2019



1.1.5 The healthcare system in Ghana

Ghana has four main healthcare delivery systems which comprise the Public, private-for-profit, private-not-for-profit and traditional systems (Aseweh Abor et al., 2008). Figure 3 provides an illustration of the healthcare system in Ghana.

Fig.3: illustration of the healthcare system in Ghana (Aseweh Abor et al., 2008)



The health system in Ghana revolves around the Ministry of Health (MOH). Operating from the capital city (Accra), where its administrative headquarters are based, the Ministry of Health (MOH) has a hierarchical structure extending from the capital city to the regions, districts and sub-districts. Healthcare delivery is done through a network of facilities: health centres and district hospitals engage in the provision of primary

healthcare services, regional hospitals provide secondary health care and the teaching hospitals (THOSP) which sit at the apex, provide tertiary healthcare (Aseweh Abor et al., 2008). The teaching hospitals play a key role in teaching by offering services for the training of physicians and other health professionals and also engage in medical and public health research. The MOH regulates the entire health sector in Ghana through its several health policies. The MOH formulate policies, coordinate as well as regulate stakeholders in the health sector. The MOH formulate policies and guidelines for health regulation by collaborating with various ministries, departments and agencies (MDAs) as well as other partners and stakeholders in the health sector (Aseweh Abor et al., 2008). These MDAs are the Ministry of Education, Ministry of Environment, Ministry of Science and Technology, Ministry of Works and Housing, and Ministry of Local Government & Rural Development. The implementation of the policies of the MOH and their reinforcement is however carried out directly and indirectly by these MDAs and other institutions working with the MOH (Abekah-Nkrumah, 2006, Aseweh Abor et al., 2008). Implementation of health policies is carried out through the private, public and traditional sectors. In the public sector, the Ghana Health Services (GHS), Teaching Hospital Boards (THB) and the Quasi Government Institution Hospitals (QGIH) are the agencies that implement the MOH's policies and reinforces its regulations (Abekah-Nkrumah, 2006, Aseweh Abor et al., 2008). The GHS has the responsibility of implementing the government's health policies and also regulates state-run health institutions [Government Hospitals (GHSP), Poly Clinics (PCs), Health Centres (HCs)]. The Ghana health services also have a secretariat that has been decentralized from the national level to the regions and districts for the purposes of carrying out its functions (Aseweh Abor et al., 2008). At each level, there is a team of management that administers the affairs of the GHS. The district teams report to the regional teams while the regional teams report to the national level team as stipulated in Act 525 of the GHS and Teaching Hospitals Act (1996). The QGIH, the last of the public sector agencies, takes the responsibility of implementing the regulations of hospitals owned by quasi-government institutions (Abekah-Nkrumah, 2006, Aseweh Abor et al., 2008). The private sector, which is also a major player in Ghana's Health Sector, is responsible for about 40 % of the healthcare delivery in the country (Abekah-Nkrumah, 2006, Aseweh Abor et al., 2008). The Private Hospitals and Maternity Homes Board (PHMHB) is the main regulatory body for the private sector. The Main healthcare providers in the private sector are the Mission-Based

providers (MBP) which mainly comprises Christian and Muslim hospitals, private medical and dental practitioners. Last but not the least, the traditional health sector is supposed to be regulated by the MOH. However, institutional and legal frameworks necessary to carry out such work is not in place and therefore, its activities are still not being regulated. In the traditional health sector, the players are Traditional Medical Providers (TMPs), Alternative Medicine (AM) and Faith-based Healers (FH) (Abekah-Nkrumah, 2006, Aseweh Abor et al., 2008).

Furthermore, Ghana operates a national health Insurance Scheme (NHIS), a form of social intervention established in 2003, which allows residents in Ghana to contribute to a fund so residents could receive affordable healthcare in the event of illness (Blanchet et al., 2012). This was set up purposely to abolish the cash and carry system in which individual health needs were only attended to after initial payment for service had been made (Agyepong and Adjei, 2008, Blanchet et al., 2012). However, the scheme has really not been effective of late, as the National Health Insurance Authority (NHIA) has yearly been reporting of inadequate contributions and funds to effectively carry out its duties. Due to the ineffectiveness of the scheme, there have been reports that many autonomous government hospitals and private ones have boycotted the scheme and have started charging patients to pay for the services. Other health establishments that have not boycotted the scheme have excluded many disease conditions that the scheme was supposed to cover. There have also been reports that many Ghanaians have still not registered under the scheme.

1.1.6 Religion in Ghana

Religion is an integral part of the Ghanaian community. Ghanaians practice three main religions, namely Christianity, Islamic and Traditional religion. Christianity happens to be the largest of these three religions (Owusu-Ansah, 1995). Christianity in Ghana dates back to the coming of Portuguese missionaries into the country (Owusu-Ansah and Berry, 1995). The Ghana Christian Council, founded in 1929, is the unifying body or organisation for Christians in Ghana (Owusu-Ansah and Berry, 1995). This body represents Christian churches such as Catholics, Pentecostals/charismatics and other protestant churches which include Methodist, Presbyterian, Baptist, Evangelical Lutheran, Episcopal Zionists, etc. (Owusu-Ansah and Berry, 1995)

The Islamic religion is the second largest religion in Ghana (Miller and Johnstone, 2015). Though there are Muslims in every part of Ghana, the Islamic religion is widespread in the northern part of the country, especially in the Dagbon area, mainly as a result of commercial activities carried out in the northern area by Muslims from the North of Africa. Muslims in Ghana are mostly Sunni who follow the Maliki School of jurisprudence (Miller and Johnstone, 2015). There is also the Ahmadiyya Muslim, the only non-Sunni Muslim order in Ghana (Miller and Johnstone, 2015). There is an excellent cordial relation between Christian and Muslims in Ghana and this relation has continued over the years. The Muslim Representative council is the body which addresses religious, social and economic matters which affect Muslims in the country (Weiss, 2004). This council is also responsible for organising the Muslim pilgrimage, known as Hajj, to Mecca (Weiss, 2004).

The traditional religious believers have also maintained their influence in the religious landscape of Ghana due to their intimate relation to family loyalties and to local mores (i.e. characteristic customs and conventions of society). The traditional cosmology, like Christians and Muslims also believe in a supreme being who they refer to in various Ghanaian languages as “Onyankopon”, “Mawu”, “Nyonmo”, etc. The traditional religious people however, do not directly worship the Supreme Being, as they believe that he is remote from daily religious life. Therefore, they worship the supreme being through lesser gods and they believe these lesser gods reside in mediums such as streams, rivers, trees, mountains etc. (Sawyerr, 1970, Pokimica et al., 2012). They believe that these lesser gods mediate between the Supreme Being and society (Assimeng, 1976, Pokimica et al., 2012). Ancestors and other spirits are also believed by the traditional religious people as lesser gods and they consider the spirit world to be real like the world of the living and believe that whatever happens in the world of the living occurs in the spirit world (Langer and Ukiwo, 2008). The ancestors are believed to be the immediate link with the world of spirits who are constantly nearer to the world of the living observing their every action (Langer and Ukiwo, 2008). As Pastors and Imams are known to be the leaders in Christianity and Islamic religions respectively, Fetish priests are mainly the leaders in the traditional religion who conduct spiritual consultations. However, Christians and Muslims in Ghana regard members of the Traditional religion as idol worshippers due to the fact that both the

Bible and Quran condemns worshipping God through mediums and spirits (Langer and Ukiwo, 2008).

As of the last National population census conducted in 2010, 71.2% of Ghana's population were Christians belonging to various denominations such as Pentecostal, Protestant, Catholics and others (Ghana Statistical Service, 2014). Table 1 portrays the religious affiliations of Ghana's Population during both the 2000 and 2010 Ghana's population census.

Table 1: Religious Affiliations in Ghana

Affiliation	2000 census	2010 census
Christian	68.8%	71.2%
Muslim	15.9%	17.6%
Traditional	8.5%	5.2%
Other	0.7%	0.8%
None	6.1%	5.2%

Ghana has a very high religious tolerance. Christmas and Easter are major religious celebrations and these are recognised as public or national holidays (Berry, 1995). There are normally vacation periods that are planned around these national holidays allowing others who may be living away from home to visit friends and families (Berry, 1995, Owusu-Ansah and Berry, 1995). The Muslim month of fasting, known as the Ramadan is also very popular in Ghana. The Muslim festival of breaking the fast, known as Idr Fetr, is recognised in Ghana as a public holiday and many Ghanaians celebrate together with their Muslim friends and family (Owusu-Ansah and Berry, 1995). There are also traditional religious festivals which are very popular in Ghana and these include festivals like Adae, Odwira and Apoo festivals (Owusu-Ansah and Berry, 1995).

1.1.8 Housing arrangement in Ghana

In Ghana, private owned compound houses dominate both the urban and rural housing stocks. These compound houses are single-storey structures that are usually built in a square or rectangle and they are roughly 30metres along each side (Tipple

et al., 1997, Whittington et al., 1993b). Along the three sides of each compound house are rooms ranging between 10 and 15 usually facing inwards onto a rectangular communal yard. The fourth side usually consists of toilet facilities, bathrooms and kitchens (Tipple et al., 1997, Whittington et al., 1993b). In other places or areas, the compound houses may also be constructed in two or three-storey forms having staircases in the courtyard that give access to galleries. These forms are mostly common in the cities along main streets. Other forms of compound houses may be built in the form of a double-bunked house at the front of the plot having a courtyard at the rear with kitchen, bathroom and toilet facilities. All households living in these compound house usually share whatever bathrooms, toilets and kitchens provided (Tipple et al., 1997, Whittington et al., 1993b). About one third of these compound houses may not have tap water and toilet facilities and households living in such houses are forced to use public water points and toilet points. In these compound houses, majority of households may occupy rooms as owners, or family members of the owners who pay no rent, or family members who hire rooms and are therefore rent-paying tenants (Tipple et al., 1997, Whittington et al., 1993b). It has been reported that about 90 % of households live in compound houses, the average single room in a compound house shelters 4.6 people, and the average number of tenants living in a compound house is about 50 (Whittington et al., 1993a).

1.1.9 Family structure, formation and family life in Ghana

The family institution is regarded as the centre of the Ghanaian society. In Ghana, the family is regarded as the bedrock of all social life. The Ghanaian family is sustained through a series of kinship networks and marriages (Van de Walle and Meekers, 1994, Lockwood, 1995). Not only is the family regarded as the basis of Ghanaian social organisations but also the family is recognised as the main source of emotional and financial security in childhood and in old age and for young people in Ghana, the family serves as the sole caretaker (Van de Walle and Meekers, 1994, Lockwood, 1995). In the Ghana region where marriage is virtually universal, marriage continues to be the main locus of reproduction and the family is regarded as the basic unit of production (Van de Walle and Meekers, 1994, Lockwood, 1995)

The traditional Ghanaian family goes beyond the conjugal unit (i.e. nuclear family). The term *family*, in everyday usage in the Ghanaian society, refers to both the nuclear and the extended family units. While the former is based on marital ties, the latter is based on the ties of kinship or lineage (Van de Walle and Meekers, 1994, Lockwood, 1995). The kinship or lineage ties identifies with two main family systems: matrilineal and patrilineal family systems. In the matrilineal system of kinship or descent, the Ghanaian society recognises that an individual belongs to the same descent group as their mother and the patrilineal system is the opposite, where individuals are considered to belong to the same descent group as their father. A large percentage of the Ghanaian society identifies with the matrilineal system. Within the matrilineal system, a married man's immediate family, apart from his wife and children, also includes his own siblings (brothers and sisters), his sister's children (i.e. maternal nephews and nieces) and his mother's brothers and sisters (maternal uncles and aunts) (Lockwood, 1995, Van de Walle and Meekers, 1994). A married woman's immediate family within the matrilineal system apart from her husband and children would also include all those mentioned above. The matrilineal system recognises that the wife is not entitled to her deceased husband's property but rather the husband's maternal family has the right to inherit the property of a deceased husband. Therefore, not only does the kinship or lineage ties go beyond the classification system but also involves relationships, rights, and obligations (Lockwood, 1995, Van de Walle and Meekers, 1994)

1.1.10. Children with disabilities in the Ghanaian family

Children are a significant part of the Ghanaian family: they are valued as a resource and therefore the family ensures that, growing up, children are equipped with the necessary training and skills to play their part in the community or society in which they live (Addai-Sundiata, 1996). Children within a household are most often the natural children of the parents, although the system of fostering out children is also accepted and practiced. In Ghana, a child is considered a member of two families : the nuclear family, consisting of the mother, the father and other children, and the extended or customary family (Addai-Sundiata, 1996) . The extended or customary family are considered to be the families of both parents. Therefore, in the Ghanaian family system, raising and caring for a child is deemed the responsibility of both the

nuclear and the extended family (Addai-Sundiata, 1996). In Ghana, children with disabilities are highly dependent on their families as they are considered amongst the most vulnerable in society. Empirical research evidences that children with disabilities and their families encounter difficult daily experiences dominated by marginalisation or ostracism, socioeconomic challenges, inaccessibility to social, health and educational facilities, inaccessibility to the built environment, discrimination and stigmatisation (Anum, 2011, Beverly and Alvarez, 2004). These findings are more profound in Ghana. For instance, children with disabilities are erroneously viewed as curses or punishment from God as a result of a parent's wrong-doing. Cultural and religious beliefs result in stigmatisation, marginalisation, and ostracism (Anum, 2011). To avoid socially constructed stigma associated with children with disability, they are likely to be hidden by their family members in the home and are kept away from public places. The Ghana Federation of the Disable (GFD) has noted that research on children with disabilities is scarce with minimal mention of advocacy services for children with disabilities and their families. However, the numbers of children with disabilities continues to rise (Anum, 2011).

1.1.11. Disability theory within Ghana's context

The disability theory has been conceptualised into two main models: The medical model and the social model. The social model has also been subcategorised into the structural and cultural models (Barnes and Mercer, 2010, Moore, 2002) These models are defined and discussed below vis-à-vis the Ghanaian context to further highlight the situation of disability in Ghana.

1.1.11.1 The medical model within Ghana's context

The medical model, also known as the individual or traditional model of disability, developed from the perspective of medical professionals, conceptualises disability as both an individual and biological problem (Barnes and Mercer, 2010). From this perspective, the person with disability is defined as the one whose bodily defects serves as an impedance to the performance of certain functions (Oliver, 1995). The medical model therefore purposes to correct or manage the bodily defects in order to enhance individual function. At the onset of disabilities, persons with disability consult health professionals to know about the diagnosis and possible cure or management

of their condition. However, the healthcare system in Ghana largely disadvantages persons with disabilities: specialised equipment and services for the management of chronic conditions such as Physiotherapy, occupational therapy, speech and language therapy, rehabilitation services, orthopaedic services, orthotic services etc. are inadequate in the Ghanaian health system (Mensah et al., 2008, Sackey, 2015). Furthermore, the National Health Insurance Scheme (NHIS) that has been instituted to ensure effective healthcare for the Ghanaian population does not cover rehabilitation and orthotic services and therefore its benefits to persons with disabilities are limited (Sackey, 2015, Mensah et al., 2008, Tinney et al., 2007). Moreover, there are no established procedures to ensure effective healthcare for persons with disabilities (Slikker, 2009, Sackey, 2015). The Ghanaian health system is designed in such a way that the care home, respite, and hospice care that exists in developed countries is not present. Hence, persons with disabilities largely depend on their families for any extra care outside the hospitals. Since 2010, the only national resource and assessment centre established for the early detection of childhood disabilities, went into dilapidation (Anum, 2011) due to lack of funds for structural maintenance. The equipment used at the centre was also affected and has not been replaced (Anum, 2011).

1.1.11.2 The structural model within Ghana's context

The structural model, a subcategory of the social model of disability, postulates that mechanisms instituted by society infringe the right to normal living for persons with disabilities. Such mechanisms include physical and environmental barriers, institutional discriminations, societal ideologies and legislations (Shah and Priestley, 2011). In terms of societal legislations, Ghana has taken a step to introduce laws that address inequalities encountered by persons with disabilities. For instance in the country's constitution crafted in 1992, article 29 expresses the need to protect the rights and wellbeing of persons with disabilities (Government of Ghana, 1992). This has also been followed by the introduction of the National Disability Act in 2006 based on which a national disability council was formed to ensure that a legislative instrument is crafted from the bill to ensure that the needs and rights of persons with disabilities are enforced and respected and to also ensure the removal of or mitigation of physical, environmental and institutional barriers. The council was charged to

oversee all disability related matters in the country and to serve as an advisory board for the government with regards to any decisions related to disability. However, it is poignant that from 2006, when the Act was introduced, a legislative instrument has not been made to ensure that the Act comes into full implementation. Therefore, situation of persons with disabilities has not changed and neither has it been improved. Persons with disabilities continue to face physical and environmental barriers, and institutional discrimination. For instance, public and private transports, public and private buildings in Ghana are largely inaccessible and there is huge underrepresentation of persons with disabilities in the various job sectors. Furthermore, Ghana accepted the Salamanca statement which advocates for inclusive education for persons with disabilities (Unesco, 1994). Thus, Ghana's Ministry of education has made it possible for children with non-severe disabilities who require special education needs to be enrolled into mainstream education. This step, although essential, has been discriminatory towards children with severe disabilities. The inclusive education, as good as it seems, has encountered several challenges which have highlighted its shortcomings. Common among these challenges are lack of teaching staff with special education expertise, architectural makeup of educational institutions and curriculum which do not favour children with disabilities, poor involvement of parents and other stakeholders, negative attitudes and perceptions of teachers towards children with special education needs (Agbeke, 2005, Kuyini and Desai, 2007, Ofori-Addo et al., 1999, Slikker, 2009).

1.1.11.3 The cultural model within Ghana's context

Culture is defined as the way of life of a people which encompasses their values, norms, religion etc. The cultural model, another subcategory of the social model of disability, states that disability is defined by culture (Barnes and Mercer, 2010). Research shows that in Africa, cultural ideologies and explanations about disabilities are deeply engrossed in traditional beliefs in which disability has been attributed to supernatural and mysterious causes (Anderson, 2004, Gureje and Alem, 2000, Ingstad and Whyte, 1995). These empirical findings also reflect Ghana's disability case as far as the cultural model is concerned (Oliver, 1995). A child with disability may be perceived as an anger, torments or punishment from evil spirits or supernatural causes. Some communities in the north hold some animals in high reverence and

believe that any harm done to such animals are believed to cause disabilities or defects in children (Agbenyega, 2003). There is also the belief that a person can use a body part for money rituals so as to become wealthy. Therefore, a wealthy person with a disability is often believed to have done some money rituals (Anderson, 2004).

1.1.12 Cerebral palsy related theories.

There are other disability and chronic illness related theories that have been utilised by some researchers as frameworks to study the cerebral palsy condition. A few of such theories will be discussed briefly in the sections that follow.

1.1.12.1 Symbolic Interactionism

Symbolic Interactionism has come into use as a label that has a relatively distinctive approach to the study of human group life and human conduct (Blumer, 1986). Symbolic Interactionism conceives the human being as active, who acts towards things, including each other, based on the meanings that the things have for them and such things may include everything the human being may see in his world. The meaning of such things arises out of the social interactions that one has with one's fellows and these meanings are handled and modified in an interpretative process used by a person in dealing with the meanings he encounters (Blumer, 1986).

Baltor and Dupas (2013) used the theory of Symbolic Interactionism to study the experiences of families of children with cerebral palsy in the context of social vulnerability. In their study, they explained that in the established interaction with the CP child and other members within the family, each family member attribute meanings to their experiences and develop strategies of care from such meanings.

1.1.12. 2 The chronic sorrow theory

The chronic sorrow theory was introduced into literature to characterize the recurrent waves of grief observed in parents of children with mental health conditions as they try to cope with the loss of a 'perfect child' (Eakes et al., 1998, Olshansky, 1962). Subsequent research has also validated the occurrence of chronic sorrow among parents of young children who have physical disabilities and have found that chronic sorrow does not only include sadness and sorrow, but other common emotions such

as fear, anger, helplessness, frustration and other emotions which are characteristic of grief (Damrosch and Perry, 1989, Fraley, 1986, Hummel and Eastman, 1991, Phillips, 1991, Seideman and Kleine, 1995, Wikler et al., 1981). The model of Chronic sorrow involves antecedents, trigger events, internal and external management methods (Eakes et al., 1998). Whittingham et.al (2013), used the chronic sorrow theory to understand the mechanism of sorrow, coping and resiliency in parents of children with cerebral palsy. They reported in light of the chronic sorrow theory that even years after diagnosis, parents of children with CP may experience intensified grief following a triggering event (Whittingham et al., 2013b).

1.1.12.3 Paterson and Zderad's humanistic theory

Paterson and Zderad's Humanistic nursing theory (Paterson and Zderad, 1976), implies an encounter among human beings which usually arises in response to a specific need related to a quality of health-disease which is usually a characteristic of the human condition (de Aguiar Lélis and Cardoso, 2014, Paterson and Zderad, 1976). This relationship often emanates from the dialogue between the nurse and the person accessing or involved in care. The dialogue is based on the communication between the nurse and the person accessing care through, but not limited to, sending or receiving messages, non-verbal messages, portraying that the caller requests help and it is the duty of the responder to promote or provide support (de Aguiar Lélis and Cardoso, 2014, Paterson and Zderad, 1976). From the literature review, de Aguiar Lélis and Cardoso (2014) utilised this theory to study the experiences of mothers with regards to facing the pain of their children with cerebral palsy. They posited that understanding how mothers of children with cerebral palsy experience the pain of the child, could assist nurses in the management of the pain of these children and also to value the presence of mothers with regards to therapeutic decisions for pain treatment.

1.2 The research condition: cerebral palsy

Cerebral palsy (CP) is a group of disorders associated with movement or motor functions that occur in the early stages of childhood development, usually before two years of age (Browne and Miller, 2005). It is caused primarily by an anomaly in the development of the brain or damage to the parts of the brain involved with movement production, which may occur during pregnancy or childbirth or shortly after childbirth

(Miller, 2005). There are variations between people regarding the signs and symptoms of this group of disorders. Common symptoms include difficulty in coordination, tremors, muscular stiffness, and weakness. Other related problems are speaking difficulties, problems in swallowing, visual defects and poor sensation (Atchison and Dirette, 2007). Unlike other children, those with cerebral palsy exhibit a delay in rolling over, crawling and sitting in the early years with more mobility and functional deficits manifesting later on as the child grows (Carnahan et al., 2007). Associated with cerebral palsy are thinking or reasoning difficulties and seizures which may occur in over one-third of people with cerebral palsy (Atchison and Dirette, 2007). Global statistical estimates show that 8000 infants are diagnosed with cerebral palsy annually (Atchison and Dirette, 2007)

1.2.1 Classification

Traditionally, CP has been classified into three categories: spastic, dyskinetic, and ataxic CP. Patients who do not fit precisely into one of these categories may be classified as mixed CP (Hagberg and Hagberg, 1996). In spastic CP there is increased muscle tone in one or more of the limbs. Dyskinetic CP is characterized by decreased or fluctuating muscle tone and abnormal involuntary movements while in ataxic CP there is a loss of orderly muscular coordination and reduced tone caused by damage to the cerebellum (Cans, 2000). More recently, however, the Surveillance of Cerebral Palsy in Europe (SCPE) network, has developed and proposed a slightly modified classification system which is now increasingly being used (Carnahan et al., 2007, Johnson, 2002, Topp et al., 2004, Himmelmann et al., 2006) Table 2 compares Traditional and SCPE classification systems.

Table 2: A comparison of the Traditional and SCPE cerebral palsy classification systems (Mutch et. al 1992 (Mutch et al., 1992), SCPE 2000(2000))

Traditional	Traditional Classification	SCPE Classification	Percentage of children
Spastic	Hemiplegia	Unilateral Spastic	85%
	Tetraplegia	Bilateral Spastic	
	Diplegia		
Dyskinetic	Mainly dystonic	Dystonic	65%
	Mainly athetotic	Choreo-athetotic	
Ataxic	Congenital (simple)	Ataxic	4.3%

Children with cerebral palsy can also be classified based on their level of motor function using the Gross Motor Function Classification System (GMFCS) (Bodkin et al., 2003, Vohr et al., 2004, Palisano et al., 1997) The system provides a classification of age-adjusted variation in 5 levels of gross motor function for children with cerebral palsy aged 1-12 (Palisano et al., 1997). In 2007, however, the GMFCS was revised to include an age band for 12-18 years (Palisano, 2007). In both age bands, distinctions between the 5 levels are based on functional limitations, use of assistive mobility devices such as walkers or crutches, use of wheeled mobility and to a lesser extent, quality of movement (Palisano et al., 2006, Palisano et al., 1997, Palisano, 2007). The different presentations of CP manifest in different physical deficits and thus may present different experiences for the child and the family.

1.2.2 Aetiology and epidemiology

The aetiology of CP is diverse and multifactorial. Multiple risk factors and aetiologies often interact hence the term “causal pathway” to describe this complex process (Blair and Stanley, 2002, Griffin et al., 2004, Reddiough and Collins, 2003). In all cases, however, there is injury or damage to the developing brain, though in most cases the precise cause of the brain damage remains unknown. Two of the most important recognized risk factors for CP are prematurity and low birth weight with the risk of CP increasing with decreasing gestational age and birth weight (Himmelman et al., 2005, Hagberg et al., 2001, Odding et al., 2006). However, although low birth weight is an important risk factor for the occurrence of CP, 95% of live births are of normal birth weight and account for more than half the cases of CP (Grether and Nelson, 1997). The risk of CP is inversely proportional to gestational age and the relative risk of CP is reported to be about 60 times higher in infants delivered at less than 28 weeks gestation than those delivered at term (Jacobsson et al., 2002). In the SCPE multicentre European study (2002), the rate of CP per 1000 neonatal survivors among babies weighing <1500g was 72.6. Among infants weighing 1500-2499g the rate of CP was 11.1 per 1000 while in those weighing \geq 2500g the rate was much lower at 1.2 per 1000 survivors. The rate of CP among children weighing less than 1500g at birth was, therefore, more than 70 times higher compared with those weighing 2500g or more at birth. While the majority of cases of CP (75 – 80%) in the developed world are most likely a result of prenatal injury with less than 10% being due to significant birth trauma or asphyxia (Sankar and Mundkur, 2005, MacLennan, 1999) the picture in

developing countries is less established. A cross-sectional study of cerebral palsy cases in Nigeria found birth asphyxia to be associated with CP in 45.7% of cases (Belonwu et al., 2009). Other associated risk factors found in that study included neonatal jaundice (12.6%), seizure disorder (11.9%), meningitis (7.3%), prematurity (3.3%) and encephalitis (2.6%), with 13.2% having an unknown aetiology (Belonwu et al., 2009). This data correlates well with earlier studies which also found birth asphyxia to be a leading aetiological factor in cerebral palsy (Karumuna and Mgone, 1990, Sathiakumar and Yakubu, 1987). Another study which was also conducted in Nigeria noted that 70.6% of the 92 children with CP reviewed belonged to lower socioeconomic groups and birth asphyxia was identified as a possible cause in 57.6% (Ogunlesi et al., 2008). The situation in Ghana has however been shown to be slightly different, with the highest risk factors for CP being severe hyperbilirubinemia, neonatal seizures, birth asphyxia, irregular menstrual cycle, preterm birth and neonatal sepsis (Adei-Atiemo et al., 2015).

1.2.3 Management

The goal of management of children with CP is not to cure or to achieve normal functioning but to improve functionality and capabilities, minimize progressive deformity, sustain health in terms of locomotion, cognitive development, social interaction and independence and manage associated problems (Kriggler, 2006, Laughton, 2004). The best clinical outcomes result from early and intensive management requiring a multidisciplinary team approach which includes paediatricians, physical therapists, orthopaedic surgeons, dieticians and occupational therapists (Kriggler, 2006, O'Shea, 2008)

Physiotherapy is the mainstay of management for the majority of children with CP (Laughton, 2004). Physiotherapy has been demonstrated to have an invaluable role in maintaining current function and reducing the incidence and severity of further complications such as joint contractures, deformities, and dislocations especially in children with significant spasticity (O'Shea, 2008, Laughton, 2004). Physiotherapy needs to be orientated towards improving the child's ability to perform activities of daily living such as improving trunk control in order to improve walking ability. Caregivers or family members also need to be taught to practice physiotherapy techniques at home on a daily basis (Laughton, 2004). The management of cerebral palsy on the African

continent, however, is limited due to the poor availability of experienced medical personnel and expertise in the management of cerebral palsy as well as shortages relating to medications and diagnostic testing limitations (Donald et al., 2015). Limited access to healthcare facilities and the lack of assistive and adaptive equipment such as wheelchairs and other ambulatory equipment have also been reported and these were noted to have contributed to the treatment gap for children with cerebral palsy (Donald et al., 2015). Even when treatment was available, families of cerebral palsy children were reported to have refrained from seeking treatment for their children due to high levels of social stigma towards these families and their children (Donald et al., 2015). The management of cerebral palsy in Ghana is done by specialist service providers such as paediatricians, neurologists and physiotherapists. These specialists are few in numbers and work in under-resourced rehabilitation centres that are mainly found in the regional and district hospitals (Cerebral Palsy Africa, 2014).

1.2.4 The chronic disease burden in Ghana: a justification for the study

Ghana has a high chronic disease burden, some of which include diabetes, asthma, hypertension, stroke and cancers (de Graft Aikins et al., 2012) Just like other global contexts, this rise in the prevalence of chronic disease, morbidity and mortality are attributed to urbanisation, transition in nutrition and the effects of globalization (de Graft Aikins et al., 2012). The chronic disease problem is compounded by a formal health system that has inadequate financial and human resources to tackle this problem and an alternative health system, the traditional healing, that provides unregulated chronic disease care (de Graft Aikins et al., 2012, Amoah, 2003, Agyei-Mensah and Aikins, 2010, Aikins, 2005). Health service delivery issues that have been identified include a lack of guidelines for the care of chronic diseases, inadequate supply of essential drugs, inadequate supply of basic equipment at health facilities and few qualified health professionals (Amoah et al., 2000, Hesse, 1995)

Childhood cerebral is one of the childhood chronic conditions that are on the rise in Ghana. Childhood cerebral palsy issues in Ghana have caused the Ghana Health Service to pay special attention to cerebral palsy in the country (Donald et al., 2014). Information on cerebral palsy issues in the country indicated that in Korle Bu Hospital, the largest referral hospital in Ghana, childhood neurologic disorders were the

complaint most presented in 1316 (5.6%) of the 22,298 new attendants that were referred over a period of ten years between 1981 and 1990. The main childhood neurology disorders that were frequently reported to the hospital were epilepsy, cerebral palsy and autism (Wilmshurst et al., 2011). Furthermore, Data output (Table 3) on cerebral palsy in Ghana by Cerebral Palsy Africa (CPA), an NGO involved in the care of children with cerebral palsy in Africa based in the United Kingdom, showed the following:

Table 3: the incidence of cerebral palsy in Ghana as compared to the UK (Cerebral Palsy Africa, 2014)

	Ghana	UK
Population	23m	62m
Children with CP to all children	1 per 300	1 per 500

This data shows that the rate of CP in Ghana may continue to increase and more children with cerebral palsy may be born into the Ghanaian population as the population increases. (Cerebral Palsy Africa, 2014). This calls for proper measures to be put in place for these children and their families. To find solutions to tackle cerebral in the country, in November 2015, the Ghana Health Service (GHS), through the Ghana News Agency (GNA) advocated nationwide training of health staff to enable them identify and help in the rehabilitation of children with cerebral palsy (CP). It has also been reported though, that what happens to these children and how their families experience and understand their disability is not known (Ghana Health Service, 2015). This report from the Ghana Health service is reflected in the findings of Donald et al (2014) who reported that qualitative studies that could assess family understanding of cerebral palsy were totally absent on the African continent. This qualitative study, therefore, purposes to explore the experiences and understandings of families having children with cerebral palsy in Ghana to help inform health practice and future policies.

1.3 Reflexivity: researcher position

Reflexivity is the research attitude of attending to the context and construction of knowledge systematically by the researcher from every step of the research process (Barry et al., 1999). It encompasses the beliefs, perspectives, and values that the

researcher brought to the study (Barry et al., 1999) as it is believed that the background and position of the researcher can affect their investigation. (Malterud, 2001)

Reflexivity creates self-awareness as the researcher considers his actions, thoughts, critiques and critical reflections of his own biases in light of the ongoing research process in order to foster more effective and impartial research conduction and analysis. As the researcher thinks reflexively through the research process by reflecting on himself and treating the research process itself as an analysis procedure, the risk of being misled by his own experiences and interpretations are mitigated or reduced (Malterud, 2001). Reflexivity in qualitative research is therefore assumed to counteract the potential impact of researcher subjectivity (Mason and Boscolo, 2002). The relationship between the researcher and participants and the influence of the research on participants are significant in the research process, and it is the key of reflexivity to make these explicit (Malterud, 2001). Reflexivity has been woven throughout this thesis and in this introductory chapter, I reflect on how this research originated and my researcher position.

Analysis of the day-to-day experiences of living and caring for a child with cerebral palsy is intended to discover the subjective meaning of the lived experience. Researchers with many years of experience (Barry et al., 1999, Finlay, 2002a, Finlay, 2002b, Palaganas et al., 2017, Primeau, 2003), suggest that reflexivity must be evident from the pre-research stage or the initial stage when the research question is being formulated. At the pre-research stage, my interest in the experience of living with a child with cerebral palsy in the family evolved from my professional background as Physiotherapy, Disability, and Rehabilitation Officer in a hospital in Ghana. Caring for children with cerebral palsy, who were usually brought by a family member for routine physiotherapy check, was part of my work. These family members were always eager to tell their stories to me during consultations and this prompted me to consider that they were struggling to find personal meanings in their subjective experience. This led me to consider the research idea of exploring the experiences of family members living and caring for a child with cerebral palsy and the meanings they constructed as a result. A review of literature also made it evident that existing studies have mostly considered the voice of the mother and the voices of other family members were rarely present. The literature evidence therefore helped in focusing the study.

1.4 Thesis Structure

In this thesis, the experiences of family members living with children diagnosed with cerebral palsy (CP) are presented. This introductory chapter has set the tone to the study by introducing the study context, overview of cerebral palsy, its classification, aetiology and management and also a justification for the study. Chapter two presents a review of the literature relevant to the study purpose and also sets out the aims and objectives of the research. Chapter three contains a presentation of the philosophical underpinnings, methodology and methods of the research. Chapter four presents the demographics of participants involved in the study. Chapters five, six and seven present the study findings based on the narrative typologies of Frank (Frank, 1995) underpinned by their themes and sub-themes derived from inductive and deductive data analysis. Chapter eight presents a critical synthesis of the results highlighting similarities, complexities and nuanced differences between participant views whiles Chapter nine presents a critical discussion of the study findings, recommendations, strengths, limitations and conclusions for the study.

CHAPTER TWO: LITERATURE REVIEW

2.1 SYSTEMISED APPROACH TO LITERATURE REVIEW

It is the aim of this chapter to contextualise the study by reviewing the literature which underpinned the current study through a systemised approach. This study was iterative and emergent in nature and this is evident in the approach taken to the literature used to underpin all aspects of the study. This chapter will show how underpinning contextual literature was identified, critiqued and used to inform the study. The focus will be on the experiences of families with children with cerebral palsy. Additional literature used to analyse and interpret the findings will be introduced in the results and discussion chapters.

2.2 Aim of the review

Quantitative studies (Krstic et al., 2015, Ribeiro et al., 2014, Al-Gamal and Long, 2013, Jeong et al., 2013, Wang and Jong, 2004, Unsal-Delialioglu et al., 2009, Sajedi et al., 2010, Pimm, 1996, Ong et al., 1998, Kaya et al., 2010, Barlow et al., 2006, Brehaut et al., 2004, Button et al., 2001, Cheshire et al., 2010, Florian and Findler, 2001, Glenn et al., 2009, Ho et al., 2008, Manuel et al., 2003, Mobarak et al., 2000, Parkes et al., 2011, Parkes et al., 2009, Sawyer et al., 2011, Skok et al., 2006, Wanamaker and Glenwick, 1998) have been conducted about families living with children with CP and these studies have focused on mainly quantifying variables such as QOL, stress, depression, and anxiety and reporting them as the essential impacts of living with children with CP in the family. These studies have failed to identify the in-depth understanding of the experiences and self-reports from individual family members in relation to social impacts, perceptions, views and needs. It is therefore the aim of this qualitative literature review to find out and synthesize the existing qualitative evidence in relation to the experiences of living with children with cerebral palsy, identify gaps in the existing qualitative literature and use these gaps to inform the current study.

2.3 Objectives of the review

The specific objectives of this literature review are:

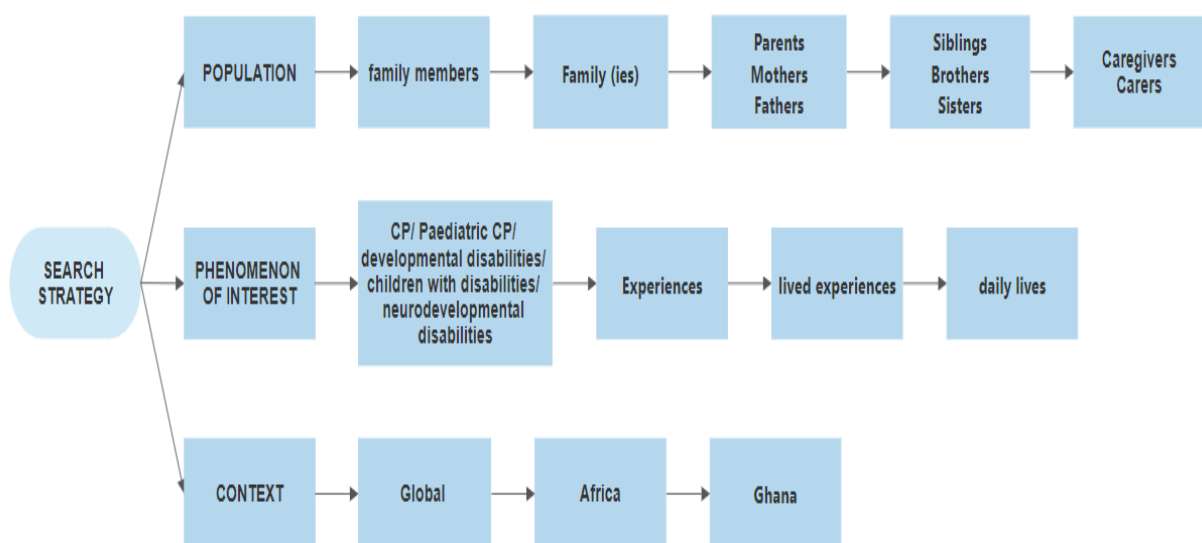
1. To identify empirical evidence about the experiences of families having children with cerebral palsy
2. To examine where and how the available research was conducted and who the study participants were
3. To synthesise the already existing information about the experiences of families with children diagnosed with cerebral palsy
4. To identify gaps in the existing research

2.4 Search strategy

The search strategy for the literature review was organised around the PPC acronym (POPULATION, PHENOMENON OF INTEREST AND CONTEXT). The PPC acronym was employed as it is seen as an effective search strategy which focuses the review of qualitative literature (Gough et al., 2013).

Figure 4 demonstrates the literature search strategy

Fig.4: Literature Search Strategy



2.5 Inclusion and exclusion criteria

Table 4 shows the Criteria for exclusion and inclusion

Table 4: Inclusion and Exclusion criteria

Inclusion criteria	Exclusion Criteria
Papers published in English	Papers not published in English
Qualitative and mixed methods studies which dated ten years back as at 2015	Studies other than qualitative and mixed methods
Papers about children with CP and their families	Papers about adults with CP and other childhood disabilities other than cerebral palsy
Papers which studied the experiences of families with CP children	Papers which studied other aspects of children with cerebral palsy and their family

2.6 Method

Health research electronic databases were searched for information related to children with cerebral palsy and their families. A literature update was done in 2019 prior to the write-up of this chapter and no new studies that fulfilled the inclusion and exclusion criteria were identified. The results of the literature review were validated by the second supervisor (CJD), by checking studies for inclusion/exclusion criteria and also cross-checking the extracted data with the original papers in order to ensure that information generated from the literature review was authentic and accurate. The results of the search are shown in table 5

Table 5: results from the search database

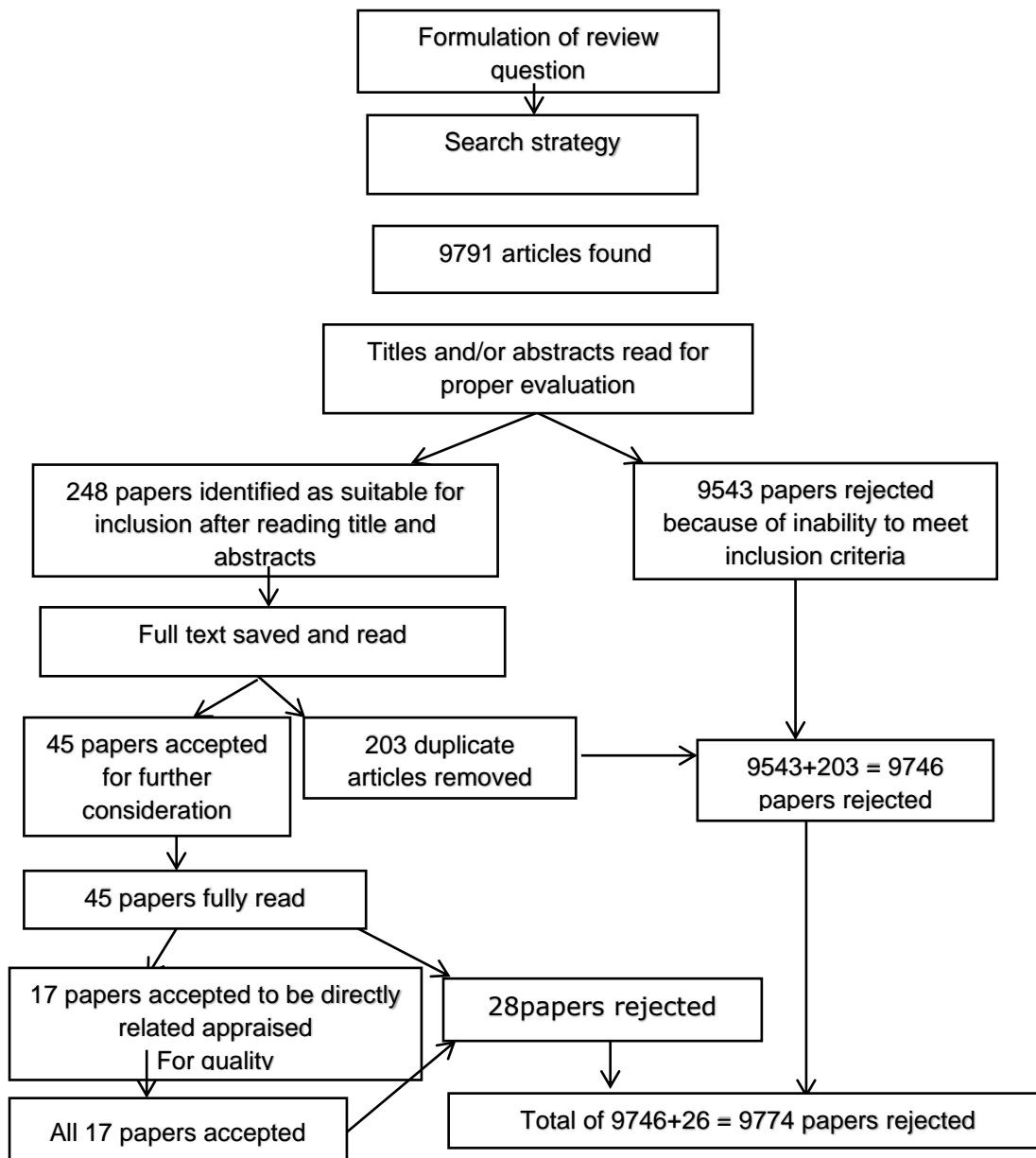
Name of Database	No. of hits	Related Papers	Extract No.	Title or abstract
PubMed	2115	61	5	Title and abstract
Cochrane	0	0	0	None
Cinahl	346	40	3	Title and abstract
Ovid	117	50	3	Title and abstract
Scopus	2113	42	2	Title and abstract
Google Scholar	5100	55	4	Title
Total	9791	248	17	

2.7 Results

Searches from all the databases yielded 9791 studies. Titles and abstracts were scanned through and 248 papers were considered for inclusion. After reading the full texts of these papers, 45 were accepted for further consideration. Seventeen research

papers were accepted from the remaining 45 as directly related to the experiences of families having children with cerebral palsy. The 28 excluded at this stage were related to adults with cerebral palsy and were therefore rejected as not meeting the inclusion criteria. Though the inclusion criteria considered mixed methods, there were no mixed methods studies that satisfied the inclusion criteria. The flowchart in figure 5 shows the results of the literature search.

Fig. 5: Flowchart for the literature search process



2.8 Summary of the study settings

A total of seventeen studies were included in this review. Two studies were from Iran (Alaee et al., 2015a, Dehghan et al., 2015b), 2 studies from the USA (Appelbaum and Smolowitz, 2012a, Glasscock, 2005), 5 studies were from Brazil (Baltor and Dupas, 2013a, Dantas et al., 2012a, de Aguiar Lélis and Moreira Leitão Cardoso, 2014, Milbrath et al., 2008a, Milbrath et al., 2009b), 2 from Spain (Fernandez-Alcantara et al., 2013, Fernández-Alcántara et al., 2015), 2 from Australia (Hayles et al., 2015a, Whittingham et al., 2011b), 2 from Taiwan, (Huang et al., 2010a, Huang et al., 2012a), 1 study from Norway (Iversen et al., 2013a) and 1 from Netherlands (Kruijsen-Terpstra et al., 2016b).

2.9 Critical appraisal of included studies

The quality of the studies included in this literature review was assessed by using a qualitative research checklist developed by Walsh and Downe (Walsh and Downe, 2006). This qualitative checklist was formed from systematic review of eight qualitative checklists for qualitative research which included : The Critical Appraisal Skills programme (CASP,1999, UK), (Cesario et al., 2002), (Mays and Pope, 2000a), (Murphy et al., 1998), (Popay et al., 1998), (Sandelowski et al., 1997), (Spencer et al., 2003) and (Yardley, 2000). This checklist was used to appraise the studies involved in the review as it was considered a most robust checklist in view of its synthesis from eight qualitative appraisal checklists. Appraisal of the included studies centred on the eight items presented by Walsh and Downe (2006), i.e *scope and purpose of the study, study design, sampling strategy, analysis, interpretation, reflexivity, ethical dimensions, and relevance and transferrability*. These are presented in the subsequent sections and table 6 presents a summary of the critiques.

Table 6 : Quality Assessment Table

Study	Scope And Purpose	Design	Sampling Strategy	Analysis	Interpretation	Reflexivity	Ethical Dimensions	Relevance & Transferability
(Alaee et al., 2015a) IRAN	Parents' experiences. Links study to contextual factors. No evidence to literature review process.	Qualitative. Design rationale not stated. No epistemology. No theoretical framework. Methods reported but no justification	Purposive sampling. Sampling strategy not justified. Detailed description of sampling procedures	Content analysis. Analysis method justified. Analysis involved more than one person. Member checking done. data saturation reached	Links study to existing literature. Verbatim quotes presented. How interpretation led to conclusion was clear	No discussion on reflexivity. Presents some evidence on tackling field issues	Ethical approval not discussed. Transparency and confidentiality. Ethical dilemma	-provides evidence for non-transferability of studies,-limitations of study not stated
Appelbaum and Smolowitz, 2012) USA	Fathers' experiences, -Does not link research to existing knowledge, -No search strategy provided	qualitative, - design rationale not stated,-,no theoretical framework, Phenomenology as method but no justification given	-Purposive sampling,- sampling strategy not justified,- sampling process described	-Thematic Analysis,-Analysis process lacking,- analysis involved more than one person,-member checking done,- evidence of reaching saturation	- links study to existing literature -verbatim quotes presented, -how	-No discussion on reflexivity -No evidence of how field problems were dealt with	- ethical approval discussed,- evidences transparency and confidentiality,- No mention of ethical dilemma	-Gives evidences to why study findings cannot be generalised nor be transferred to other settings, -limitations of study not stated
(Baltor and Dupas, 2013a) BRAZIL	Experience of families. Poor literature review. No contextual factors established . No search strategy provided	-Qualitative,- design rationale not stated. Symbolic interactionism as theory,-no epistemology. Methods reported but no justification	Snowballing, - sampling strategy not justified,-no detailed sampling process	- content Analysis, - Brief description of analysis approach, -Analysis done by one person,-No member checking done,-No evidence of reaching data saturation	Does well in linking studies to existing literature. Links interpretation to conclusion. uses verbatim quotes from study findings	-No discussion on reflexivity-No presentation on field problems and how these were dealt with	-No evidence of ethical approval -No information on transparency and confidentiality	-No discussions on how studies may fit other contexts -Limitations and weaknesses not made explicit

(Dantas et al., 2012a) BRAZIL	-Family (mothers) experience s-very little literature review. No search or terms	-Qualitative,- design rationale not stated.-No theoretical framework,-No epistemology,- methods but not justified	-Purposive sampling,-- sampling strategy not justified,- sampling process not clear	-Thematic Analysis,-Clear description of analysis process,- Only one researcher involved,-No member checking done,-No evidence of reaching data saturation	Does well in linking studies to existing literature. A link between interpretation and conclusion. Use of verbatim quotes.	No evidence of researcher reflexivity. Does not comment on field problems that might have been encountered	-no comments on ethical approval for the study -gives information on confidentiality and transparency	-how findings may fit or be transferred to other contexts not stated. -limitations or weaknesses of the study not stated
(de Aguiar Lélis and Moreira Leitão Cardoso, 2014) BRAZIL	Experience of mothers. No contextual literature. no contextual literature. No search strategy or terms	-Qualitative study. No rationale given for choosing a qualitative study. Phenomenology , uses theory. Methods not justified.	-type of sampling not explicit,- sampling process not clear	-Phenomenological Analysis,-The Analysis process was not documented,-no comments on data saturation,-no member checking done.	-discusses findings with reference to existing literature ,-uses verbatim quotes from study participants in interpreting findings	-no detailed discussion on reflexivity but gives evidence to researcher participant relationship,- does not comment on field problems	-no section on ethical approval for the study	-how findings may be transferred to other contexts not stated,- no explicit limitations or weaknesses shown
Dehghan et al., 2015) IRAN	Experience of mothers. cites contextual literature – no search strategy or terms	-Qualitative, No rationale for choosing qualitative study. No theory. No epistemology. Methods not justified	-no explicit sampling method,- sampling process not clarified	Content Analysis.Data Analysis process clearly explained. Data saturation not stated. no member checking done	-findings are clearly linked to existing studies. Uses verbatim quotes in interpreting findings.	No discussion on reflexivity. No comments on field problems encountered	-study does not report on ethical approval. no evidence for transparency and confidentiality	-how findings may be transferred to other contexts not stated -no explicit limitations and weaknesses are shown
(Fernandez-Alcantara et al., 2013) SPAIN	Parents experience . No contextual literature. no search	-Qualitative study,-No rationale given for choosing a qualitative study,-No theoretical	-no explicit sampling method.- sampling process not clarified	-type of data analysis not explicit,-data analysis done with Atlas.ti 6.2 software following a strategy of open coding.,--	-links findings to existing literature. verbatim quotes are used as examples in	-No discussion on reflexivity,- no evidence of research participant relationship,-no comments on	-fails to report on ethical consent for the study. transparency and confidentiality not evident	- transferability of findings to other settings not documented,- limitations and weaknesses are not reported

	strategy or terms	framework,- No epistemological underpinning shown, unjustified methods		evidence of data saturation not stated,-no member checking done	interpreting findings	field problems encountered		
(Fernández-Alcántara et al., 2015) SPAIN	- experience of fathers and mothers,- evidence of existing literature,- No search strategy	-Qualitative study,-rationale not given,- Grounded theory,-No epistemology Unjustified methods	-purposive sampling ,- not justified,- detailed sampling process	-uses constant comparison and justifies it's preference -more than one researcher -no evidence of saturation	-links discussion with relevant existing and contextual literature -verbatim quotes shown	-No reflexivity shown,-No research participant relationship evidence, -no field problems highlighted	- evidence of ethical approval,- ensured transparency and confidentiality	-Transferability not evidenced,-No highlighted limitations and or weaknesses
(Glasscock, 2005) USA	Mothers' experience . Summary of literature search shown but no search terms	-Qualitative study. Rationale not given. uses Phenomenology as epistemology and justifies why that it was chosen	-used convenience sampling but did not justify its use -no detailed sampling procedure	-Phenomenological Analysis. Justifies its use. Gives detailed analysis procedure.one member involvement. Member checking done	Inadequate discussion section. Does not link discussion with any existing literature. verbatim quotes shown	-No detailed discussion on reflexivity but gives evidence of a good researcher-participant relationship -No highlighted field problem	- evidence of ethical approval -ensured transparency and confidentiality	-Transferability not evidenced -No highlighted limitations and or weaknesses

Hayles et al., 2015) AUSTRALIA	- experience of parents,-- few links to literature -No search strategy	-Qualitative study,-rationale not given,-uses social constructivist epistemology and grounded theory methodology and justifies them	convenience and purposive sampling but no justification,- detailed sampling process	-used constant comparative Analysis but provides no justification,-gives detailed and well-planned analysis procedure,-more than one member involvement,- Evidence saturation.No member checking	-links findings to existing and contextual literature in the discussion section.,- verbatim quotes shown	-No detailed discussion on reflexivity but gives evidence of a good researcher-participant relationship,- field problems encountered not reported	-evidence of ethical approval -evidence of transparency and confidentiality	-Transferability not evidenced -No highlighted limitations and or weaknesses
(Huang et al., 2010a) TAIWAN	-Mothers' experience -good contextual information and literature. no search terms or strategy	-Qualitative study,-rationale not given. uses hermeneutic Phenomenology as a qualitative method and provides justification	-uses purposive sampling and provides justification,- sampling procedure clearly spelt out	-used hermeneutic phenomenological analysis but how it was carried out was missing in the report. one member involvement. no member checking	-links discussion to existing literature but not contextual ones. linked interpretation to conclusion. verbatim quotes shown	No detailed discussion on reflexivity but gives evidence of a good researcher-participant relationship. Reports field problems	-evidence of ethical approval -evidence of transparency and confidentiality	-Transferability not evidenced -No highlighted limitations and or weaknesses
(Huang et al., 2012a) TAIWAN	Mothers' experiences-very little contextual factors cited. No search terms or strategy	-Qualitative study. Rationale not given. hermeneutic phenomenology with justification	- Purposive sampling but no justification. Sampling procedure not detailed.	-Hermeneutic analysis. One member involvement. No member checking. no evidence of reaching data saturation	used quotes from study participants in the interpretation of findings.-good linkage between interpretation and conclusion	-No detailed discussion on reflexivity but gives evidence of a good researcher participant relationship. No report on field problems	-ethical approval evident. evidence of transparency and confidentiality between researcher and participants	-no evidence for rigour, validity and transferrability limitations and weaknesses shown

(Iversen et al., 2013a) NORWAY	Experiences of parents. Few citations for background literature. No search strategy nor terms	-Qualitative study. Rationale not given. hermeneutic phenomenology with justification	-no explicit sampling strategy -no explicit recruitment process	-Hermeneutic analysis -provides a detailed analysis procedure, -no evidence of data saturation, -no member checking, -one member involvement	compare findings with existing literature. conclusion not made explicit, -usage of very few verbatim quotes in the interpretation of study findings	-No detailed discussion on reflexivity but gives evidence of a good researcher-participant relationship, -reports field problems and how they were resolved	-evidences ethical approval, -reports field problems and how they were resolved, transparency and confidentiality were established	-no evidence on how rigour was ensured -no discussion on validity, reliability and transferability
(Kruijsen-Terpstra et al., 2016) NETHERLANDS	Experiences of mothers, -- good contextual literature. No search terms or strategy	-Qualitative study. Rationale not given. Methods not justified. no epistemology	-purposive sampling -clear sampling procedure	-Thematic Analysis, -gives a clear analysis procedure, -no evidence of data saturation, -no member checking, -one member involvement.	-Uses quotes in interpreting findings, -Links findings to existing literature and contextual literature	-No detailed discussion on reflexivity but gives evidence of a good researcher-participant relationship, -reports field problems	Evidences ethical approval. Transparency and confidentiality of information between researchers and participants	-provides no evidence on the transferability of study findings -limitations of study reported, -no evidence of study rigour,-
(Milbrath et al., 2008a) BRAZIL	Experiences of mothers. No contextual literature. No search terms or strategy	-Qualitative study. Rationale given. No epistemology. Methods not justified	Random sampling but no justification, sampling procedure clarified	-Thematic Analysis. Clarifies analysis process, -no member checking. One member involvement. No evidence of data saturation	-report on study findings and the interpretation of findings not in-depth	-No discussion on reflexivity, -field problems not reported	-evidences ethical approval -transparency and confidentiality were ensured	-no evidence on how rigour was ensured, -no evidence on the transferability of study findings, -limitations not reported

<p>(Milbrath et al., 2009b) BRAZIL</p>	<p>Experiences of mothers. No contextual literature. No search terms no strategy</p>	<p>Qualitative study. Rationale given. No epistemology. Methods not justified</p>	<p>Purposive sampling but no justification, sampling procedure clarified</p>	<p>Thematic Analysis, clear on analysis process, - member checking done, - one member involvement, data saturation,</p>	<p>Reports on findings and interpretation not in-depth, - cites very few literature in discussion</p>	<p>-No discussion on reflexivity,- field problems not reported</p>	<p>- sought ethics approval, transparency and confidentiality were ensured</p>	<p>-no evidence on how rigour was ensured, - no evidence on the transferability of study findings, - limitations reported</p>
<p>(Whittingham et al., 2011b) AUSTRALIA</p>	<p>Experiences of parents, references existing, no search strategy</p>	<p>-Qualitative study-rationale given, No epistemology, Methods not justified</p>	<p>-no explicit sampling strategy,- unclear procedure</p>	<p>Thematic Analysis, clear on analysis process, - no member checking , -one member , saturation</p>	<p>Links findings to existing literature</p>	<p>No discussion on reflexivity,- field problems not reported</p>	<p>-evidences ethical approval, - transparency and confidentiality not evident</p>	<p>- no evidence provided for rigour, transferrability and validity, no limitations reported</p>

2.9.1 Scope and purpose of studies

The experiences of mothers dominated these studies as nine of the studies (Dantas et al., 2012b, de Aguiar Lélis and Cardoso, 2014, Dehghan et al., 2015a, Glasscock, 2000, Huang et al., 2012b, Huang et al., 2010b, Kruijsen-Terpstra et al., 2016a, Milbrath et al., 2009a, Milbrath et al., 2008b) focused on the mother only. Five studies (Alaee et al., 2015b, Fernández-Alcántara et al., 2013, Fernández-Alcántara et al., 2015, Hayles et al., 2015b, Iversen et al., 2013b) focused on the experiences of parents; except one study (Iversen et al., 2013b) which recruited equal number of mothers and fathers (six each), all the other four showed a higher number of mothers than fathers. Only one study (Appelbaum and Smolowitz, 2012b) looked into the experiences of fathers alone. One study (Baltor and Dupas, 2013b) reported the experiences of six families taking into consideration the views of mothers, fathers and sisters without specifying the specific numbers of each group. However, the results of this study (Baltor and Dupas, 2013b) portrayed a higher amount of information from mothers than any of the family members. This was evident in the number of quotes presented in the study which informed the interpretation of the results. Out of the twenty-six quotes used in the results, twenty quotes were from mothers, three were from fathers and three were from sisters. This suggests that the views of mothers were represented more than the others. One study (Whittingham et al., 2011a) considered the experiences of parents and healthcare professionals. Thus, it appears that the voice of the mother dominates the existing literature, less of the father's voice is represented and experiences from other family members are rarely reported.

All authors in the various studies categorically stated their rationale and purposes of conducting the research. However, all studies with the exception of Glasscock (2005), failed to report their search strategy for the existing literature referenced in their documents and all seventeen did not show any search terms. Failure to report search strategy and search terms are likely to affect the credibility, transferrability, dependability and/ or confirmability of all these studies (Downe et al., 2007).

2.9.2 Design

With the exception of three papers (Milbrath et al., 2008a, Milbrath et al., 2009b, Whittingham et al., 2011b), which stated their rationale for adopting a qualitative research, all the remaining fourteen papers failed to do so. All papers stated the specific methods used in the study but eleven of these (Alaee et al., 2015b, Appelbaum and Smolowitz, 2012b, Baltor and Dupas, 2013b, Dantas et al., 2012b, Dehghan et al., 2015a, Fernández-Alcántara et al., 2013, Fernández-Alcántara et al., 2015, Kruijzen-Terpstra et al., 2016a, Milbrath et al., 2009a, Milbrath et al., 2008b, Whittingham et al., 2011a) did not provide any justification for why such methods were chosen. Out of the seventeen papers, only seven (Appelbaum and Smolowitz, 2012b, de Aguiar Lélis and Cardoso, 2014, Glasscock, 2000, Hayles et al., 2015b, Huang et al., 2012b, Huang et al., 2010b, Iversen et al., 2013b) were able to demonstrate an epistemological standpoint and among these seven, two (Appelbaum and Smolowitz, 2012b, de Aguiar Lélis and Cardoso, 2014) were not able to justify the choice of their epistemology.

2.9.3 Sampling strategy

Five studies (de Aguiar Lélis and Moreira Leitão Cardoso, 2014, Dehghan et al., 2015b, Fernandez-Alcantara et al., 2013, Iversen et al., 2013a, Whittingham et al., 2011b) did not show any evidence of a specific sampling method. Of the twelve that did, only three (Hayles et al., 2015a, Huang et al., 2010a, Kruijzen-Terpstra et al., 2016b) documented their reason for choosing a specific sampling method and the remaining 9 provided no justification. Of the twelve papers which stated their sampling methods used, two reported using convenience sampling (Glasscock, 2000, Hayles et al., 2015b) , Eight used purposive sampling (Alaee et al., 2015b, Appelbaum and Smolowitz, 2012b, Dantas et al., 2012b, Fernández-Alcántara et al., 2015, Huang et al., 2012b, Huang et al., 2010b, Kruijzen-Terpstra et al., 2016a, Milbrath et al., 2009a), one used random sampling (Milbrath et al., 2008b), and snowballing (Baltor and Dupas, 2013b) . Purposive sampling therefore has been the sampling method used frequently in these studies.

Eight studies (Alaee et al., 2015a, Appelbaum and Smolowitz, 2012a, Fernández-Alcántara et al., 2015, Hayles et al., 2015a, Huang et al., 2010a, Kruijzen-Terpstra et al., 2016b, Milbrath et al., 2008a, Milbrath et al., 2009b), demonstrated clarity on their

recruitment process during actual data collection and nine papers did not show how the recruitment process was conducted.

2.9.4 Analysis

Apart from one paper (Fernández-Alcántara et al., 2013) which did not specify the method of analysis used, all others reported their specific method of data analysis. Of the sixteen papers which reported the analysis method used, six used Thematic analysis (Appelbaum and Smolowitz, 2012b, Dantas et al., 2012b, Kruijsen-Terpstra et al., 2016a, Milbrath et al., 2009a, Milbrath et al., 2008b, Whittingham et al., 2011a), five used phenomenological analysis (de Aguiar Lélis and Cardoso, 2014, Glasscock, 2000, Huang et al., 2012b, Huang et al., 2010b, Iversen et al., 2013b), three reported using content analysis (Alaee et al., 2015b, Baltor and Dupas, 2013b, Dehghan et al., 2015a) and two employed the use of constant comparative analysis (Fernández-Alcántara et al., 2015, Hayles et al., 2015b). Thus, thematic analysis has been the type of analysis that has frequently been used. However, the analysis process provided by five of these studies (Appelbaum and Smolowitz, 2012a, Baltor and Dupas, 2013a, de Aguiar Lélis and Moreira Leitão Cardoso, 2014, Fernández-Alcántara et al., 2015, Huang et al., 2010a) were not detailed and lacked clarity. Moreover, only seven of these papers (Alaee et al., 2015a, Appelbaum and Smolowitz, 2012a, de Aguiar Lélis and Moreira Leitão Cardoso, 2014, Hayles et al., 2015a, Milbrath et al., 2008a, Milbrath et al., 2009b, Whittingham et al., 2011b) provided information about reaching data saturation during the analysis process. The other ten did not document anything about data saturation.

On researcher involvement during the analysis process, five papers (Alaee et al., 2015a, Appelbaum and Smolowitz, 2012a, Dehghan et al., 2015b, Hayles et al., 2015a, Whittingham et al., 2011b) reported the involvement of more than one researcher in the data analysis. Member checking after data analysis provides the opportunity to study participants to find out whether the findings of the study reflect their actual experiences narrated to the researcher (Walsh and Downe, 2006). With the exception of three papers which showed evidence for member checking (Alaee et al., 2015a, Appelbaum and Smolowitz, 2012a, Glasscock, 2005), all the other papers had no documentation about member checking.

2.9.5 Interpretation of findings

Almost all the studies used verbatim quotes from study participants in interpreting their findings and referred to relevant literature during discussion. However, one paper (Glasscock, 2005), interpreted results of the study but did not show any discussion section. As such how the findings were linked to existing literature could not be seen.

2.9.6 Researcher reflexivity

One of the key tenets of qualitative research distinguishing it from quantitative research is researcher reflexivity. It is imperative that some reflexivity is reported so that the reader can sense how the whole project was shaped by the researcher (Walsh and Downe, 2006). It includes the relationship between the researcher and study participants, effects of the research on the researcher, evidence of how field problems and complications were met and dealt with, self-awareness or insight (Walsh and Downe, 2006). Seven papers (de Aguiar Lélis and Moreira Leitão Cardoso, 2014, Glasscock, 2005, Hayles et al., 2015a, Huang et al., 2010a, Huang et al., 2012a, Iversen et al., 2013a, Kruijsen-Terpstra et al., 2016b) discussed the relationship between the researcher and the researched but did not give a full account of reflexivity in the whole research process; the rest did not discuss this. With the exception of one paper (Alaee et al., 2015a) which reported how field problems were met and dealt with, none of the others provided information on dealing with field problems. Therefore, most of the papers failed to provide an audit trail for the research activities and the repeatability or a duplication of their processes in other settings becomes questionable.

2.9.7 Ethical dimension

Being sensitive to and respecting the status of study participants is visible through ethical approval procedures which are mandatory (Walsh and Downe, 2006). Ethical considerations are based on protecting individuals from harm which includes guaranteeing of confidentiality, anonymity and informed written consent (Walsh and Downe, 2006). Many researchers even take this further by giving explicit information to participants at all stages of the research process and attempting to make sure that study subjects receive respect, transparency and openness (Miller et al., 2012).

Ten studies (Appelbaum and Smolowitz, 2012a, Fernández-Alcántara et al., 2015, Glasscock, 2005, Huang et al., 2010a, Huang et al., 2012a, Iversen et al., 2013a,

Kruijzen-Terpstra et al., 2016b, Milbrath et al., 2008a, Milbrath et al., 2009b, Whittingham et al., 2011b), gave evidence of ethical approval before the studies were carried out; the rest did not document the approval of ethics in their report. Furthermore, with the exception of four studies (Baltor and Dupas, 2013a, Dehghan et al., 2015b, Fernandez-Alcantara et al., 2013, Whittingham et al., 2011b) all the other papers assured transparency and confidentiality with their study subjects .

2.9.8 Relevance and transferability

Three of these studies provided evidence of the validity, reliability and probable transferrability of their study by providing evidence for rigour (Glasscock, 2005, Hayles et al., 2015a, Huang et al., 2010a) all the others provided no evidence of the standards adopted to ensure rigour in their studies. Furthermore, only four papers (Hayles et al., 2015a, Huang et al., 2010a, Huang et al., 2012a, Kruijzen-Terpstra et al., 2016b) documented the limitations and weaknesses in their study. As the critiques on all the studies have been presented in this section, the next sections would present a synthesis of the research evidence published by these studies.

2.10 Thematic synthesis of findings from various studies

Based on (Lucas et al., 2007a) criteria for meta-synthesis, thematic synthesis for the findings of each study were done to identify major themes. Findings from all seventeen studies were collated. It was judged from reading and re-reading of the collated findings (Lucas et al., 2007b) that five areas of enquiry were evident and these were:

- 1) Emotional distress
- 2) Changes in family orientation and priorities
- 3) Trust and Mistrust in healthcare professionals
- 4) Negative societal attitudes
- 5) The need for family support.

Data and themes were therefore grouped into these areas and emerging themes were considered for relevance and presence across studies (Lucas et al., 2007b). This process was repeatedly carried out until all data could be interpreted through these themes (Lucas et al., 2007b). Five major themes were therefore identified based on the five areas of enquiry. Table 7 shows the number of papers that identified each theme.

Table 7: Thematic synthesis of relevant studies

Paper	Theme				
	Emotional distress	Change in family orientation & priorities	Trust & mistrust in healthcare professionals	Negative societal attitudes	Need for family support
Alaee et al., 2015a				X	
Appelbaum and Smolowitz,					X
Baltor and Dupas, 2013a		X		X	
Dantas et al., 2012a		X			X
de Aguiar Lélis and Moreira Leitão Cardoso, 2014	X				
Dehghan et al., 2015a	X	X		X	X
(Fernandez-Alcantara et al., 2013		X			
Fernández-Alcántara et al., 2015	X				
Glasscock, 2005					X
Hayles et al., 2015a			X		
Huang et al., 2010a	X		X		X
Huang et al., 2012a				X	
Iversen et al., 2013a			X		
Kruijzen-Terpstra et al., 2016b	X		X		
Milbrath et al., 2008a	X	X			X
Milbrath et al., 2009b					X
Whittingham et al., 2011b			X		

2.11 Themes

The themes identified from thematic synthesis of the study findings comprised *Emotional distress*, informed by findings from six studies (de Aguiar Lélis and Cardoso, 2014, Dehghan et al., 2015a, Fernández-Alcántara et al., 2015, Huang et al., 2010b, Kruijzen-Terpstra et al., 2016a, Milbrath et al., 2008b) , *changes in family orientation and priorities*, informed by five studies (Baltor and Dupas, 2013b, Dantas et al., 2012b, Dehghan et al., 2015a, Fernández-Alcántara et al., 2013, Milbrath et al., 2008b) , *Trust and Mistrust in Healthcare Professionals*, a theme resulting from five studies (Hayles et al., 2015b, Huang et al., 2010b, Iversen et al., 2013b, Kruijzen-Terpstra et al., 2016a, Whittingham et al., 2011a), *Negative societal attitudes*, from four studies (Alaee et al., 2015b, Baltor and Dupas, 2013b, Dehghan et al., 2015a, Huang et al., 2012b) and *the need for family support*, contributed by seven of the studies (Appelbaum and Smolowitz, 2012b, Dantas et al., 2012b, Dehghan et al., 2015a,

Glasscock, 2000, Huang et al., 2010b, Milbrath et al., 2009a, Milbrath et al., 2008b). These themes are presented in the sections that follow.

2.11.1 Emotional distress

Six of the studies included in the review revealed that having a child with cerebral palsy causes emotional distress for the family (de Aguiar Lélis and Cardoso, 2014, Dehghan et al., 2015a, Fernández-Alcántara et al., 2015, Huang et al., 2010b, Kruijsen-Terpstra et al., 2016a, Milbrath et al., 2008b). The extract below illustrates the above theme:

“I felt that was the end of the world. ...I felt I had dropped from heaven to hell, so I wasn’t able to feel joyful and be happy about giving birth to my son. It was sad and miserable to face a problem like this. People’s expectations are always of a healthy, happy, vigorous baby. But my son didn’t meet these expectations.”(Huang et al., 2010a)

Upon learning that their child had been diagnosed with cerebral palsy, mothers experienced a loss of the ‘ideal child’, a loss of the expectation of normal motherhood and a loss of fulfilling societal anticipation of giving birth to a healthy child (de Aguiar Lélis and Moreira Leitão Cardoso, 2014, Huang et al., 2010a). Parents expressed their greatest moments of emotional distress related to the birth of the child (Fernández-Alcántara et al., 2015, Whittingham et al., 2013b). Parents experienced trauma, shock and others had trouble speaking about the condition of their child and there were some who expressed denial when they doubted that their child had no cerebral palsy (Fernández-Alcántara et al., 2015, Whittingham et al., 2013b). Many parents, especially women, expressed feelings of sorrow and desperation. Shock and sorrow were predominant especially during the diagnosis period and the sadness and sorrow increased when parents started assimilating the news of the loss of the child they anticipated. Issues in the parents’ discourse centred around constant comparison between the actually born child and the expected child. Thoughts of the child they longed for, the one with whom they could perform many activities, was etched in their memory (Fernández-Alcántara et al., 2015). Mothers underwent mixed feelings of disbelief, rejection, self-blame and sadness and they felt great uncertainty about the future of their children (Huang et al., 2010a). Questioning and guilt were also

interspersed with an ambiguity of feelings, including fears, anxieties, dedication and love for the child (Milbrath et al., 2008a). Another study from Iran also reported that the mother's grief was more related to her child's condition and more especially when the mother saw a healthy child and compared him to her child (Dehghan et al., 2015b). Contrary to this, however, Fernández-Alcántara et al. (2015) also reported a number of parents expressed positive emotions. These emotions related to hopes and expectations of what their child would be able to achieve. Many of the parents interviewed in this study also reported that they had perceived themselves as laypeople at the time when their child started therapy but overtime, most of the parents felt confident and were more empowered (Fernández-Alcántara et al., 2015). Whilst the studies identified here have explored the emotional distress of parents, this has only been considered mostly during the time of diagnosis with little attention having been paid to the longer-term impact.

2.11.2 Change in family orientation and priorities

Another theme that emerged was a change in family orientation and priorities (Baltor and Dupas, 2013b, Dantas et al., 2012b, Dehghan et al., 2015a, Fernández-Alcántara et al., 2013, Milbrath et al., 2008b). This theme is also illustrated by the extract below:

“Well, the changes were all, in general, like this, our life changed completely all of a sudden because it was only me and my husband, and suddenly there came a son, and with a handicap. I think that when I became aware of the care he needed my entire life changed “(Milbrath et al., 2008a)

The experiences from six families (Baltor and Dupas, 2013a), showed that cerebral palsy had great impact on the family by causing the family to mobilize and reorganise itself to find ways of caring for the special needs of their child with cerebral palsy. Caring for the Child with CP was seen as a priority and the time allocated for the child's caring interfered with the occupation of at least one of the family members (Baltor and Dupas, 2013a). Similarly, Fernández-Alcántara et al. (2015) reported that the mode of relation with the child with infantile cerebral palsy was different from that with other children as parents were more focused on the possibility of improvement in the child with CP. Changes in the different aspects of the lives of these parents were shown,

such as time demands, labor and economic situations as well as a threat to the relationship between the couple. Having a child with cerebral palsy was shown to significantly impact mothers' lives by limiting their ability to interact socially and professionally with people outside of the home environment (Dehghan et al., 2015b, Milbrath et al., 2008a). Dantas et al. (2012) also add their voice to the changes caused in the family as a result of having a child with cerebral palsy. Difficulties in dealing with seizures, spasticity, and changes in postural tone, often made the performance of daily living activities like feeding, bathing, and locomotion difficult for the children with CP, which in turn, caused changes in the lives of parents as they always had to be around to support the child (Dantas et al., 2012a). These studies reported that changes that occur in the family were found to be mostly related to the social and economic lives of family members, particularly mothers and there is a lack of studies on how the social and economic lives of other family members are affected. Moreover, the findings of these studies may not fit other contexts, such as the Ghanaian or African ones because social and economic lives differ in different settings. This raises the need to conduct different studies within different contextual factors and settings.

2.11.3 Trust and mistrust in healthcare professionals

Family members demonstrating a trust and mistrust in health professionals is also another theme that came out from the synthesis of data. Five studies (Huang et al., 2010a, Iversen et al., 2013a, Kruijzen-Terpstra et al., 2016b, Hayles et al., 2015a, Whittingham et al., 2011b) from the review have considered this. The extract below supports this theme:

“She was at her correct age of three months. She was unable to lift her head and her whole body was just too floppy. I told the doctor...The doctor answered, ‘Oh, premature babies are usually slower in achieving their developmental milestones. That will be fine.’ ...the doctor kept saying it was okay when she was six months old. One day the Premature Association Foundation...came to do develop-mental tests on my daughter. ...Wow, you know the outcome of the test. My daughter had problems with developmental delays in many areas. It was just like a thunderbolt hit my head”. (Huang et al., 2010a)

Huang et al. (2010) reported that the mothers in Taiwan felt that healthcare professionals were careless or lacked sufficient knowledge about cerebral palsy to ensure that their child received optimal medical assessment and diagnosis. Some mothers lost trust in healthcare professionals and their own ability to make care decisions (Huang et al., 2010a). For some study participants, the condition of their child was delayed before being diagnosed because in their opinion, the healthcare professionals did not conduct thorough and careful physical examinations or failed to suggest seeking further opinions. Iversen et al. (2013) and Whittingham et al. (2011) present a somewhat mixed opinion. They reported mothers' experiences with healthcare professionals as an ambivalent situation. They felt vulnerable and very much dependent on healthcare workers' competence and the same time doubted them in seeing and taking care of their child's specific needs. Findings from two other studies (Kruijsen-Terpstra et al., 2016b, Hayles et al., 2015a) were consistent with part of the findings of Iversen et al. (2013). They stated that parents relied on healthcare professionals and often expressed a need for information, in particular on cerebral palsy in general, regarding their child's therapy and information about what to expect for their child's future. They suggested that parents and therapists often built up a partnership concerning the child's interventions and this was especially evident when it came to making decisions. The growth of this partnership depended on both parents and therapists and their roles and the extent to which parents wanted to be involved influenced the development of the partnership. The needs in the therapy process differed between parents but were also found to change over time (Kruijsen-Terpstra et al., 2016b). These studies highlighted the varied relationships and trust between parents and healthcare professionals and the lack of study of siblings and other family members.

2.11.4 Negative societal attitudes

Parents or families of children with CP have been suggested to experience negative societal attitudes towards them and their children; four studies identify this theme (Baltor and Dupas, 2013a, Dehghan et al., 2015b, Huang et al., 2012a, Alaei et al., 2015a).

“At a religious ceremony, people were just staring at me and my child for a few seconds, till I looked at them and then they looked away. I will get really

upset. My child sits there, all of the people quit the ceremony and were staring at us. For this reason, I do not go out unless I need to go to a ceremony or feast”(Dehghan et al., 2015b)

Mothers faced negative societal attitudes where they suffered when seeing the ignorance of people who did not understand and respect the condition of their children (Baltor and Dupas, 2013a, Alaei et al., 2015a). They reported negative behaviours from other people which included staring, displaying pitying expressions, meddling and stating faulty logic and beliefs (Dehghan et al., 2015b). Due to this marginalisation, some mothers felt reluctant at times to come out with their children to seek professional support (Huang et al., 2010a) whilst others tried to maintain their presence in society by managing these challenging negative attitudes from society and even attempted to provide a context for mutual enjoyment for mother and child (Dehghan et al., 2015a). Other negative social attitudes included curiosity and inappropriate questions, lack of the understanding and little or no acknowledgement for the troubles that parents go through and a lack of acceptance of the child's condition. Other mothers experienced stigma which manifested in society's judgment of them through blames and reprimands, as a result of having children with cerebral palsy (Alaei et al., 2015b).

2.11.5 Need for family support

The need for family support was the last theme that emerged and was evident in seven of the studies (Dantas et al., 2012a, Dehghan et al., 2015b, Glasscock, 2005, Huang et al., 2010a, Milbrath et al., 2008a, Milbrath et al., 2009b, Appelbaum and Smolowitz, 2012a) Mothers described how they relied upon strong family relationships during difficult times (Glasscock, 2005, Appelbaum and Smolowitz, 2012a). The extracted quote supports this theme.

“Mother K has three naturally born children including a two-year-old son with CP. She also has three adopted daughters with special needs. This family has cared for children with special needs for 29 years. Their son with CP is the youngest child. Mother K receives assistance and social support from her husband, children, Mother K talked about family by saying: My husband does a lot of grocery shopping... He does laundry, the dishes, change diapers... He does more homework and stuff with the other kids to free me so that I can work with him. He's not much on cooking... he'll put it

out or in the microwave, but I cook... I do the last minute things with the girls helping me..."(Glasscock, 2005)

Dantas et. al (2012) also reported that strengthening relationships within families by improving their bonds and developing quality and comprehensive actions, promoted the welfare of the family or child with cerebral palsy. Milbrath et al. (2008) also highlighted the need for family support. They suggested that although the mother is considered the direct caregiver of the child with special needs, they inferred she needed to use social support networks that would be able to help her fulfil her own needs, as well as the child's. In this social support network, the family was noted as the main unit, serving as the link to provide the necessary support (Milbrath et al., 2008a). In this study, mothers were found to need psycho- socioeconomic support from their families and the people who surround them, in both the process of initial adaptation and overcoming and the whole period of care for the child (Milbrath et al., 2008a). A similar study by the same authors in 2009 (Milbrath et al., 2009a) revealed that the main difficulties faced by mothers were related to the family's understanding and acceptance of the birth of the child into the family (Milbrath et al., 2009b). Mothers who received physical, mental and financial support from the family were usually able to care well for the child and also participated in their normal social and economic activities. However lack of family support could result in the mother becoming more depressed about the situation of the child and more isolated (Dehghan et al., 2015b). This section reveals how support from the family is important for mothers caring for children with CP. Mothers are able to care for these vulnerable children when they get support from the family.

2.12 Insights and gaps from the existing literature

Whilst some research has been done into the experiences of living with children with cerebral palsy, there are gaps that could be addressed in further research.

- ❖ In studying the experiences of families having children with cerebral palsy, existing qualitative literature has centered mostly on the experiences of mothers, the voice of the fathers is less often heard and the voices of others such as, siblings and extended family members are almost insignificant in literature (Huang et al., 2010a). Taking a whole family approach could offer a

better understanding of the experiences of living with children with CP in the family.

- ❖ The differences and similarities between the experiences of family members living with children diagnosed with Cerebral palsy are not evident in literature.
- ❖ The findings of this study may not be transferable to other contexts such as the Ghanaian or African context; social and economic lives differ in different contexts. There is therefore the need of conducting studies on the experiences of living with a child with cerebral palsy within different settings.
- ❖ Most of the studies involved in the review failed to utilise a theoretical framework; as a result, explanatory models which enhance the understanding of living with children with cerebral palsy are lacking.

2.13 Relevance and scope of the proposed study

To fill some gaps in the existing literature, this study explored the experiences of living with a child with cerebral palsy; it employed a multiple participant perspective by including the voices of additional family members to gain understanding of the experience of living with a child with cerebral palsy. The study, as one of its objectives, will endeavour to find out the similarities and differences between the multiple participant views as this is not evident in the cerebral palsy literature. The review has made it evident that explanatory or theoretical frameworks are lacking in the cerebral palsy qualitative literature; this study will also endeavour to develop a theoretical framework to further enhance the understanding around living with a child with cerebral palsy.

2.14 Research question

What are the experiences of family members living with children with cerebral palsy?

2.14.1 Objectives

The objectives for this proposed study address some of the gaps and deficits discussed in the existing literature

- ≈ *To explore the experiences of individuals living with the child with CP in the family by employing multiple participant perspective*
- ≈ *To explore similarities and differences between the different family members*

- ≈ *To identify what meanings could be inferred from the experiences of these individual members*
- ≈ *To develop a theoretical model or employ an explanatory framework which would enhance the understanding of living with a child with cerebral palsy in the family in order to inform clinical practice*

2.15. Conclusion

This chapter has presented a systematic literature review of the relevant studies on the experiences of living with children with cerebral palsy in the family. Significant gaps were identified from this review. Theories that have also been used to study chronic illness experiences identified from the literature search have also been presented. It has also demonstrated that the research aim and objectives of the current study were developed based on some of these gaps.

CHAPTER THREE: EPISTEMOLOGY, THEORETICAL FRAMEWORK AND METHODOLOGY

3.1 Introduction

This chapter will present the epistemology, research approach, theoretical framework, methodology and methods adopted in this study. The literature review has shown the gaps in knowledge and limitations of most studies concerning the experiences of living with children with CP. Quantifying variables such as quality of life, depression, anxiety, the severity of disability have been the focus of most quantitative studies, thus these variables have been reported as the essential impact of living with children with cerebral palsy in the family. Qualitative studies (Alaee et al., 2015b, Appelbaum and Smolowitz, 2012b, Baltor and Dupas, 2013b, Dantas et al., 2012b, de Aguiar Lélis and Cardoso, 2014, Dehghan et al., 2015a, Fernández-Alcántara et al., 2013, Fernández-Alcántara et al., 2015, Glasscock, 2000, Hayles et al., 2015b, Huang et al., 2012b, Huang et al., 2010b, Iversen et al., 2013b, Kruijzen-Terpstra et al., 2016a, Milbrath et al., 2009a, Milbrath et al., 2008b, Whittingham et al., 2011a, Whittingham et al., 2013a, Zuurmond et al., 2015) which endeavoured to look into the situation of living with children with CP in the family have been critiqued to exhibit questionable credibility, transferability, dependability and/ confirmability suggesting the need for more research work with high methodological rigour. Existing research is dominated by the voice of the mother and less of the father's voice; the voices of other family members are rarely reported. Therefore, this research proposes that hearing the voices of other family members living with children with CP could bring a holistic understanding of the experiences these members go through in daily life.

3.2 Research approach: qualitative study

The qualitative research approach has been chosen as a suitable approach for this study and was informed by the works of Denzin & Lincoln and Van Maanen (Denzin and Lincoln, 1994, Denzin and Lincoln, 2005, Van Maanen, 1998). Qualitative research is considered to be a type of research that uses a realistic and interpretive approach towards its subject matter and also places an emphasis on processes and meanings occurring naturally (Denzin and Lincoln, 2005). Furthermore, qualitative research is employed as an approach to studying an occurrence in its natural environment supported by social meanings from individuals who were subjected to the

occurrence (Denzin and Lincoln, 1994). This current study looks into the experiences of the family members of children with CP as these experiences occur naturally when these members care for the child with CP in daily life. It is noted by Denzin and Lincoln (2005) that qualitative research can also be used to address questions that relate to how social experiences are created and how meanings are given to these experiences. This study explores the meaning in use by family members of children with CP to explain how they directly experience everyday life realities in caring for these children. Qualitative research has a humanistic and inherent literary focus and uses the talks and words of individuals to give meaningful representations to their experiences (Denzin and Lincoln, 2005). This study has used the narratives of family members of children with CP to give a meaningful representation of the experiences they go through in living with and caring for these children with special needs. The words of these individual family members have helped with the description of the meaning of living with a child with cerebral palsy from the real-life settings of these individual family members. Qualitative research can be employed to provide robust insights from actions that have occurred in real-life contexts and to preserve the meaning intended, which gives forms and understanding of underlying social processes and meanings (Van Maanen, 1998). The idea of qualitative research providing insights into real- life context falls in line with the purpose of this study, as this research explores the real life situation of living with a child with CP in the family. Qualitative methodology, therefore, as opposed to quantitative, can provide an empirical understanding of the essence or nature of the experience of living with a child with CP in the family

3.3 Overview of research questions and objectives

The purpose of any research is to discover answers to questions by following standard and accepted procedures of enquiry (Kothari, 2004). Therefore in any research work, the research question, the aims and objectives are of great importance since they inform the choice of the research design and methods to be used (Kothari, 2004, Bowling, 2014). The proposed research question for this study was “*what are the experiences of family members living with children with CP*”? To address this research question, the main objectives of this study were:

- ≈ *To explore the experiences of individuals living with the child with CP in the family by employing multiple participant perspective*
- ≈ *To explore similarities and differences between the different family members*
- ≈ *To identify what meanings could be inferred from the experiences of these individual members*
- ≈ *To develop a theoretical model or employ an explanatory framework which would enhance the understanding of living with a child with cerebral palsy in the family in order to inform clinical practice*

3.4 Epistemology, methodology and methods

Epistemology can be thought of as the nature of knowledge and its justification (Carter and Little, 2007). The methodology is the “theory and analysis of how research should proceed” (Harding, 1987, Carter and Little, 2007), it calls for the analysis of the assumptions, principles and procedures in a particular approach to enquiry (Schwandt, 2001). In short, a methodology is that which justifies the methods of a research project (Carter and Little, 2007, Kaplan, 1964). Methods can be thought of as the action involved in the conduct of an enquiry. Methods are the techniques for gathering research data (Carter and Little, 2007, Harding, 1987, Schwandt, 2001). It is the purpose of this chapter to demonstrate the epistemological position of this thesis, theoretical framework, and methodology.

3.5 Epistemology: pragmatism

Researchers are considered to make certain assumptions concerning how and what they will learn during the process of their enquiry. Lincoln and Denzin call these assumptions or claims paradigms (Denzin and Lincoln, 2011), Crotty calls them philosophical assumptions or epistemologies (Crotty, 1998), and they are broadly conceived by Neuman as research methodologies (Neuman, 2000). There are many epistemological paradigms or assumptions in which the world is viewed. These can be perceived as epistemological lenses and different lenses necessitate different assumptions in which the world can be understood (Collins, 2010).

Pragmatism, a philosophical tradition that originated in the United States around 1870 has been adopted as the epistemological lens for this study. The most important pragmatists, known as *classical pragmatists*, were Charles Sanders Peirce, William

James, and John Dewey. Other important scholars who have contributed and supported pragmatism over the years, known as *neopragmatists*, include the likes of Richard Rorty, George Herbert Mead, W.V.O Quinine, Cornel West, Richard Bernstein, Wilfrid Sellers, Nelson Goodman, Hilary Putnam, Donald Davidson, and Cherryholmes. The work of Lee Cronbach also became increasingly pragmaticized in the course of his career (Cherryholmes, 1992). This research has combined views from classical pragmatists and neopragmatists. Its assumptions being pluralistic, pragmatism involves research designs that incorporate operational decisions based on ‘what will work best’ in finding answers for the questions under investigation (Creswell and Clark, 2007, Stewart, 2011). Pragmatism counters the dogmatism that is upheld by methodological purists and this enables pragmatic researchers to conduct research in innovative and dynamic ways to find solutions to research problems (Johnson and Onwuegbuzie, 2004).

Trying to find an answer to the research question posed in this study, I adhered to the pragmatist philosophy that the best way to seek this answer was to adopt the research actions that would work best in this interest. In this section, I am able to outline the key tenets of pragmatism as they were applied to this study. The key tenets of pragmatism applied in this study are listed in Table 8. These characteristics and how they were applied will be discussed in the succeeding paragraphs.

Table 8: Tenets of pragmatism applied in the study

The key tenets of pragmatism which have been applied in this study
<ul style="list-style-type: none"> ▪ Rejects traditional philosophical dualisms but prefer more moderate and common-sense philosophical dualisms based on how well they work in solving the problems under investigation ▪ Views knowledge as being constructed based on real-world experiences ▪ Meaning is created from human experience ▪ Views truth as tentative, changing over time ▪ Understands human experience through language and communication ▪ Advocates human rights and individual freedom; An enquiry should bring relief and benefit the condition of man ▪ Accepts human enquiry as being analogous to scientific and experimental enquiry ▪ Endorses theories that inform practice (Practical theory)

Rejection of Traditional Philosophical dualism

Pragmatism accepts common sense philosophical dualisms based on their relevance to finding questions to problems under investigation, thereby rejecting traditional and dogmatic philosophical dualisms (Cherryholmes, 1992, Johnson and Onwuegbuzie, 2004). Many traditions of research, from empiricist/ positivist (quantitative tradition) to Phenomenological/ Interpretivist (qualitative tradition) and to some versions of the critical research tradition aim at getting things right. In the words of Dewey (1930), these traditions “insist upon antecedent phenomena when reporting and registering past experiences” (cited in Cherryholmes, 1992 p. 13). These traditions insist that descriptions, theories, and explanations must precede values and social policy but for pragmatists, a search for descriptions, theories, explanations, and narratives must be preceded by values and visions of human action and interaction (Cherryholmes, 1992, Cherryholmes, 1988). Pragmatic philosophy asserts that choices about what to research and how to go about it must be conditioned by where we want to go in the broadest sense (Cherryholmes, 1992) Following the path of pragmatism, there is the need to ask what difference does it make in conducting a piece of research one way rather than the other and this points to the choice of the research goals (James, 1995). Pragmatism asserts that choosing between one position and the other is somewhat unrealistic in practice, and it is argued that the most important determinant of which position to adopt is the research question. This is particularly relevant where the research question does not seem to suggest clearly which methodology should be adopted for the enquiry (Creswell and Clark, 2007) . Cherryholmes, one of the neopragmatists, writes:

“The pragmatic response is that we have no way of knowing; our choice simply means that one approach is better than another at producing anticipated or desired outcomes” (Cherryholmes, 1992)

This means that Pragmatism offers individual researchers the freedom of choice and it also means that researchers are free to choose their methods, techniques and research procedures that will best meet the needs and purposes of their enquiry. This concept of pragmatism coincides with my position as a researcher. At the beginning of this research study, I sought out how best to answer the research question. I started by searching for the relevant empirical literature to find out what was already known about this question and what was yet to be discovered. Finding the gaps in literature

led me to decipher the best and most appropriated way to address some of these literature gaps.

I did not adopt any methodological stance at the beginning and refrained from developing the aims and objectives of the research to fit a particular methodology. I was open to all qualitative research methodologies to determine the best way of finding a solution to the question under investigation. I considered the option of using phenomenology as both a philosophy and methodology. I realised that when less is known about a phenomenon under study, it is better to adopt the transcendental phenomenology, where the researcher is supposed to set aside his previous experiences when interacting with study participants. Setting aside my experiences could not be done due to the reason that my previous experiences gained through daily interactions with family members of children with cerebral palsy as Disability and Rehabilitation Practitioner would help me ask important questions during the data collection phase, hence the rejection of phenomenology. Initially, case study methodology was also considered as a potential methodology for this enquiry. With this methodology, the child with CP in the family would have been the potential centre of the case surrounded by family members but since this research was interested in the voice of family members rather than that of the child, case study methodology was rejected. Obviously, Ethnography couldn't be used in this study since this study is not about studying or observing the way of life of a particular culture. The final decision then made was that the most pragmatic way to answer the research question posed in this study was to use the Generic qualitative design, a methodology which does not pay allegiance to any methodological tradition but open to all traditions and may adopt methods from these traditions as and when appropriate for the purpose of this study.

Knowledge and knowledge construction

The pragmatist philosophy views knowledge as being constructed based on the reality of the world we experience and live in. This encompasses not only past realities but also possible realities of the future. Real-world experiences determine the knowledge and quality of knowledge that one has (Nowell, 2015). The pragmatist philosophy provides an epistemological justification for bringing together multiple sources of knowledge with the aim of finding radical solutions and also to gain a greater understanding of people and the world in which we live, practice and solve individual

problems as well as social ones (Johnson and Onwuegbuzie, 2004). This philosophy of pragmatism resonates with the purpose of conducting this study. Knowing about the reality of living with a child with cerebral palsy from a complex reality such as clinical physiotherapy and rehabilitation practice, where knowledge may not always converge but may sometimes vary and may also contradict, calls for multiple perspectives to be considered. With recognition of the diverse way of knowing as legitimate truth, the breadth and depth of knowledge which may be gained from multiple truths can bring a larger understanding and insight into larger complex truths. The literature review exploring the experiences of living with a child with cerebral palsy identified that the experience of the mother has been mostly considered as the pending and most relevant knowledge. However, experiences from other members of the family could challenge the way in which living with a family member with cerebral palsy is viewed.

Meaning is created based on experience

Dewey promoted pragmatism by moving philosophy away from abstract concerns and centred it on human experience (Dewey et al., 1991, Dewey et al., 2008). According to Dewey (1991) experience was built around these two questions which cannot be separated: “*what are the sources of our beliefs? And, what are the meanings of our actions?*” Dewey (1991) theorised that answers to these questions are linked in a cycle. He identified that the origins of our beliefs are from our prior actions and that our beliefs influence the outcome of our actions. He emphasized that present situations are influenced by past experiences and future moments are impacted by the experience of the present. From Dewey’s epistemological standpoint, beliefs from our previous experiences can be interpreted to generate action and then actions can be in turn be interpreted to generate beliefs (Morgan, 2014, Dewey et al., 2008, Dewey et al., 1991). Dewey also saw enquiry as a kind of experience. He saw enquiry as a process of making choices by asking questions and finding answers to these questions, where those concerns raised during the enquiry process can inform future actions to resolve a problem. This characteristic of pragmatic philosophy walks hand in hand with the purpose of my research. As part of my research objectives, I sought to identify the experiences of living with children with cerebral palsy from the daily life experiences of family members. I believe that the experiences of these family members could bring out inferred meanings that could inform clinical practice and

could, in the future, inform stakeholders for the planning of interventions for these families.

Truth is transient and changes overtime

From James' (1995) point of view, Pragmatism is basically an epistemological undertaking keynoted by its theory of truth and meaning. This theory states that truth can be known only through its practical consequences and is thus an individual or a social matter rather than an absolute truth (Blackburn, 2005, James, 1995).

Pragmatism views current truth, knowledge, and meaning as tentative and changes over time (Johnson and Onwuegbuzie, 2004). Pragmatism states that truth is not stagnant and therefore James (1995) states that what we call today as truth, we must be ready to call it falsehood tomorrow (James, 1995, Johnson and Onwuegbuzie, 2004). Pragmatism accepts that truth is what works and in this considers truth as fallible, provisional and revisitable as it is only considered truth while it works best (Nowell, 2015, McCready, 2010). According to James, truth is infinite and it emerges from facts which are added to again and again so as to create or reveal new truth (James, 1995, Nowell, 2015) This core tenet of pragmatism falls in line with my belief in conducting this research. Clinical research means a continual search to create new knowledge or truth for the improvement of professional practice. In light of pragmatism, truth or knowledge created from clinical research must be viewed as provisional truth. This, therefore, means that the truth or knowledge about living with children with CP in the existing literature is not the absolute truth but must be added on again and again through successive research works.

Understanding of human experience through language and communication

Dewey believed that language and communication can actually represent or symbolise a given social or physical reality and that there is a correspondence between the world and our words and between reality and our descriptions of that reality (Dewey et al., 1998). At the core of Dewey's entire philosophy of pragmatism is his view of language as a tool for the construction of meaning. Dewey's view of language is stated below:

“Through speech, a person dramatically identifies himself with potential acts and deeds; he plays many roles, not in successive stages of life but in a contemporaneously enacted drama” (Dewey et. al., 1998, pp.52)

Individual minds emerge when they have the capacity to engage or participate in social activities involving the use of language as a tool (Dewey et al., 1998).

In volume 2 of Dewey's book, *Ethics, Logic, Psychology* (Hickman and Alexander, 2009), edited by Hickman, he stated that:

"As to be a tool, or to be used as means for consequences, is to have and to endow with meaning, language, being the tool of tools, is the cherishing mother of all significance" (Hickman and Alexander, 2009, pp.58)

In this research enquiry, I believe in the Philosophy of Dewey that language could be used as a tool to understand the meaning of living with a child with CP in the family. I strongly believe that talking and interacting with the family members of the child with CP has helped in gaining a meaningful understanding of how these members have lived, felt, undergone, and made sense of their experiences so as to give a thoughtful and thorough description of these experiences (Oquist, 1978). Thus as a method of data collection, I have engaged with family members living with children with CP through interviews and believe that the information they have given clearly reflects the real daily life experiences of living with a child with CP as they wish to portray it.

Advocacy for human rights and individual freedom

According to Richard Rorty's pragmatist theory, he argues that the function of any enquiry is to bring relief and benefit to the condition of man, to make humans happier by enabling them to cope more successfully with their conditions and with each other (Rorty, 1982).

This concept of pragmatism is in tune with my purpose of conducting this research. My interest in the experience of living with a child with CP in the family is to gain an understanding of the experiences of living with a child with cerebral palsy to inform potential future interventions.

Human enquiry as analogous to scientific and experimental enquiry

An enquiry is a process by which problematic beliefs are examined and resolved through proper actions. The process of enquiry involves making choices by asking and answering questions that concern the likely outcomes of applying current beliefs or knowledge to future action (Morgan, 2014). According to Dewey, there is no sharp

boundary between everyday life and research. Instead, research as an enquiry is performed more carefully and more self-consciously than most other responses to problems (Dewey et al., 2008, Dewey et al., 1991, Morgan, 2014) . Human enquiry (what people do in their day-to-day lives as they interact with their environment) is viewed by pragmatists as similar or performs the same function in certain respects as the scientific method. They believe that humans try out new things to find out what works, what can solve problems and what helps us to survive. Warranted pieces of evidence are obtained that provide answers which are ultimately tentative and in the long run, this moves us towards larger truths (Johnson and Onwuegbuzie, 2004) This characteristic of pragmatism supports my epistemological belief in this study. I believe that what family members living with children having cerebral palsy experience in their day-to-day lives as they care for the child with cerebral palsy could be studied and constructed as scientific knowledge to inform clinical practice. Furthermore, in constructing knowledge from the experiences of these people, I aligned this research process to Dewey's (2008) pragmatic five-step approach to enquiry. Dewey's five-step approach to an enquiry, can be summarised as follows:

Recognizing a situation or condition as problematic

- 1) *Taking into consideration the difference it makes in defining a problem one way rather than another*
- 2) *Finding or developing possible lines of actions to find a response for the problem*
- 3) *Evaluation of potential actions in terms of the likelihood of their consequences*
- 4) *Taking actions that are deemed likely to address the problem*

With reference to these steps, I discovered from the existing literature that there is a problem surrounding the situation of living with a child with CP in the family because the existing literature has considered mostly the experiences of the mother hence partial experiences are presented in the literature as the truth. Knowing about the experiences of other family members is important, especially in developing settings, at it is the cultural norm in developing settings like Ghana, for both nuclear and extended families to live together and support each other. A broader picture was therefore needed in the literature to properly clarify this situation. Hence, I defined my research question (i.e. *what are the experiences of family members living with children*

with CP?) in a way that would incorporate broader views from many members in the family. To find and develop possible lines of action to make the situation of living with a Child with CP in the family clearer, I adopted a qualitative methodology and methods (*discussed at the methodology and methods section*) that I believe have brought out answers to better clarify this problem. Actions taken to seek broader views (discussed in the methods section) were properly evaluated (ethics section) before actual data collection began. These actions did not cause any harm to study participants. The last approach in Dewey's five steps is for one to take actions that are deemed likely to address the problem. I believe the findings that this enquiry has brought out are an improvement upon the existing literature with reference to credibility, dependability, and/or confirmability and also this study has provided a new way of listening to and understanding cerebral palsy stories. Hence the findings could be taken by any individual, clinical and academic institutions, research bodies, governmental organisations, etc. who are planning to develop some interventions for family members living with Children with CP or to simply provide an understanding for those who deal with children with cerebral palsy and their families

Endorsement of theories that inform practice

One important tenet of pragmatism is that it endorses theories that inform practice or in other words, it endorses practical theory (Morgan, 2014). Pragmatism views theories as instrumental and true, and that they are true to different degrees based on how well they currently work. Pragmatism judges theories on the criteria of their predictability and applicability (Morgan, 2014). This characteristic of pragmatism supports one of the objectives of my research with reference to how theories are applicable to research. In this research, the use of Frank's illness narrative typology has been useful as a theoretical framework in enhancing the understanding of living with a child with cerebral palsy in the family and how this theory could be used to inform the practice of healthcare professionals who may be involved in dealing with children with cerebral palsy and their family members.

3.6 The adopted theoretical framework: Frank's illness narrative typologies

One of the most important aspects of the research process is the adoption of a theoretical framework because it serves as an anchor for the data analysis (Osanloo and Grant, 2016). Frank's narrative typologies of illness were adopted because it appeared participants shared their experiences through stories and their stories presented narrative plotlines that could be explained by Frank's narratives. From his book *The Wounded Storyteller*, Frank argues that the identification of narratives is the "most general storyline that can be recognised underlying the plot" (Frank 1995, p.75). They can be of benefit in portraying how people attempt to make sense of their experience, construct meaning for their experiences, give an indication of how they want their story to be interpreted and the identification of the common cultural frameworks participants use to structure events and experiences. Therefore, writing about his own experience of testicular cancer and also from non-fiction illness stories, he suggested three types of illness narrative genres which comprise, Restitution, Chaos and Quest (Frank, 1995). Frank further suggested that in any illness, all his three types of narrative genres would be told "alternatively and repeatedly" and that at one moment in an illness, one narrative typology may guide the illness story. However, the story would be told through other narrative types as the illness progresses. Thus Frank asserted that "the particularity of any experiential moment can thus be described by the narrative type that predominates at that moment" (Frank, 2013, p.103). He proposed that the movement of the narrative types are like patterns in a Kaleidoscope, in which the different colours appear in one specific form at a given moment but another colour emerges with the shifting of the tube. Frank further stressed that each of the narrative genres reflects "strong cultural and personal references" but however, the strength of such preferences presents a barrier to listening to the ill person because institutions and listeners may steer narrators towards certain genres and leave other narratives unheard. He described these three narrative genres as devices that enhance or aid in listening to illness stories by helping the listener to identify similar and/or contradictory narrative trends (Frank, 1995, France et al., 2013). Therefore, Frank's narratives are of important significance to research as the genres allow the examination of individual, social and cultural influences on narratives of illness. The three typologies could also be of benefit to researchers, professionals and relatives of the ill person to better understand a particular illness through listening to

the illness narratives. Frank's narrative typologies of restitution, chaos and quest are presented in the subsequent sections.

3.6.1 The restitution narrative

Frank (1995) posited that the restitution narrative is the culturally preferred narrative genre, gains promotion from biomedical healthcare and is also reflected in popular culture. It reflects a natural desire to get well and stay well (Frank, 2013). The restitution plotline is characterised by "Yesterday I was healthy, today I'm sick but tomorrow I'll be healthy again (Frank 1995, p.77). This narrative is focused on the restoration of the previous state of health of the ill person. Frank, however, stated that when illness becomes terminal or chronic, restitution stories no longer work or can no longer be constructed. According to Frank, the restitution narrative will dominate most stories, particularly those who have some recent illness and the least often would be people suffering from chronic illness. This is because anyone who falls sick wants to get his or her health back again and moreover, modern culture also treats the healthy state as the normal condition that ought to be restored when people fall sick. Therefore, Frank stressed that the desire of the ill person to get well is also compounded by others' expectations to hear restitution stories (Frank, 2013). In restitution narratives, the storyline is full of talks about tests and their interpretation, possible outcomes from treatments, assessment of the competence of physicians or health professionals and alternative treatments (Frank, 2013). He further proposed three ways in which restitution stories could be told: prospectively, retrospectively and institutionally. According to Frank (2013) institutionalised restitution narratives model how illness stories are to be told. They adopt the biomedical perspectives of getting ill and the possible outcome of getting well. Retrospective restitution stories look into the past, through the lens of biomedicine and recount actions taken to aid the occurrence of restitution. Prospective restitution stories look into the future, assimilating various illness outcomes and hopes for restitution to occur based on biomedical perspectives (Frank 2013, p. 106). Frank theorised that the most pervasive and insidious model of the restitution story are television commercials for non-description medicines which happens in three movements. In these movements, the sick person is shown in commercials as a person in physical misery. In the second movement, another person comes into the scene offering a remedy. Though the ill person is hesitant in taking the remedy, he eventually takes it in the third movement and health is finally restored.

These commercial movements have pervaded society and have contributed to society making restitution the preferred narrative. Living in contemporary society, people assimilate such commercials unconsciously without even noticing them. Hence when an illness surfaces, people automatically would desire restitution to occur (Frank, 2013, p. 106). Just as the restitution narrative projects a future that will not be disrupted by illness, it also protects memory from disruption. In the restitution narrative, memory is not disrupted because the present illness is an aberration, a blip in the otherwise normal passage of illness. The stories of restitution are powerful and compelling because oftentimes, they are true. This is because many people are able to recover from illness sooner or later. However, as a limitation, restitution stories no longer work when the ill person is dying or when an impairment remains chronic. In this case, other stories will have to be prepared by the teller otherwise there could be a likelihood of narrative wreckage (Frank, 2013)

3.6.2 The chaos narrative

Frank (1995) proposed that the opposite of restitution is the chaos narrative: "Its plot imagines life never getting better" and a loss of control (p. 97). Chaos narratives "are told after your world has been 'unmade'" (p. 103); they can be characterized as "anti-narratives" because "those who are truly living chaos cannot tell it in words" (p. 98) and the narrative has no temporal order. Frank suggested that chaos narratives are difficult to hear because they provoke anxiety. In their absence of narrative order, stories become chaotic in nature and events are narrated "without sequence" or discernible cause. The lack of sequential coherence makes stories of chaos harder to hear. In chaos, the teller is understood by the audience as not telling a proper story, and more significantly, the chaos storyteller "is not heard to be living a proper life", because in stories, it is expected that one event should lead to another in sequence but chaos leads to negating this expectation. The preference of restitution stories over chaos, makes chaos stories anxiety-provoking. Within chaos stories, are embedded all that modernity seeks to avoid or surpass. In chaos, the modernist defences of remedy, professionalism, progress and advances in the restoration of health crumble, revealing futility, impotence and vulnerability. Whereas the restitution narrative presents possibilities in which suffering could be outwitted or outdistanced, the chaos narrative typology presents how anyone could be sucked under suffering. Restitution stories provides the listener with a reassurance of a happy ending regardless of how

grim or bad things may look. Frank (1995, 2013), likens the biblical Job “with his new family and cattle, basking in God’s graciousness” to a restitution story while at the same time he likens “Job’s wife advising him to curse God and die”, as chaos story. In chaos, there is a lack of control on the part of the ill person and this lack of control is compounded by medicine’s inability to cure the condition. Therefore, people living chaos stories regularly blame or accuse medicine “for seeking to maintain its pretence of control—its restitution narrative—at the expense of denying the suffering of what it cannot treat” (Arthur, 2013, p.128)

3.6.3 The quest narrative

Stories of restitution render illness as a transition by attempting to outdistance mortality. In chaos stories, there is the portrayal of being sucked into the undertow of illness and its’ attending disasters. In contrast, quest stories “meet suffering head-on”, accept illness and “seek to use it” (Frank, 2013). In the quest narrative, “illness is the occasion of a journey that becomes a quest” (Frank, 2013, p.142), However, that which is actually quested for may not be entirely clear but the quest is given a definition through the ill person’s belief that “something is to be gained through the experience (Frank, 2013, p.142). Whilst restitution and chaos focus storytellers on remedy and loss of control respectively, it is the quest narrative that gives storytellers a voice as tellers of their own stories because “only in the quest narrative does the teller have a story to tell”. Frank (2013, p.146), saw quest stories as very broad, hence, he sub-categorised them into three facets: *the quest memoir*, *the quest manifesto* and the *quest auto mythology*.

The *memoir* is a combination of the illness story with other events in the storyteller’s life. It can also be described as an “interrupted autobiography” (Frank, 2013, p. 146). In the memoir, events are not chronologically told and life is not rehearsed in detail. It is known to be the gentlest quest story style.

The *auto-mythology* form of quest portrays the author as one who has survived and reborn. The tellers of auto-mythology would expand illness to also reveal faith or destiny (Frank, 2013, Whitehead, 2006).

The *manifesto* is the least gentle type of quest. It asserts that illness is a social issue, not simply a personal affliction. It witnesses how society has added to the physical

problems that disease entails, and it calls for change, based on the solidarity of the afflicted. The adoption of the narrative typologies of Frank as a theoretical framework in this study occurred during the time of data analysis. Section 3.8.9.2 of this chapter will demonstrate how the underpinning theoretical framework of this study was arrived at.

3.7 Methodology: generic qualitative methodology

Qualitative research makes an effort to understand unique situations as part of a defined context and the interactions there (Merriam, 2002a). Qualitative research does not attempt to predict what future happenings are likely to be but rather tries to understand the nature of a particular setting, what it means for participants to be in that setting, the nature of their lives, what goes on in that setting and what their meanings are (Merriam, 2002b). In qualitative research, the researcher is the primary instrument for data collection and analysis. The researcher can expand his understanding through both verbal and non-verbal communication and process data immediately from his interaction with participants. The product of any qualitative enquiry is a rich description and interpretation. Words and pictures instead of numbers are used to report what a researcher has learned about a particular phenomenon. To support the findings of the study, data in the form of quotes from documents, field notes, interviews, excerpts from videotapes, electronic communication may be included in qualitative studies (Merriam, 2002b).

The generic qualitative research methodology is an interpretive and descriptive study that exemplifies all the characteristics of qualitative research described above. With this methodology, the researcher is interested in understanding how individuals make meaning of a phenomenon or a situation. This meaning is reported through the researcher as the mediator, as does many qualitative works. It has an inductive strategy and a descriptive outcome (Merriam, 2002b). The generic qualitative methodology is a design which does not declare allegiance to any single established qualitative methodological tradition (Kahlke, 2014). Studies using the generic qualitative design, exhibit some or all of the characteristics of qualitative endeavour but instead of focusing the study through the lens of an established tradition, they do one of three things: combination of several traditions, drawing on a single established tradition and deviating from its intent, guidelines or rules, in a way that may be very

beneficial for the study, or no traditional viewpoint is claimed at all. (Caelli et al., 2003). Advocates of the generic qualitative methodology, argue that established traditions must not be treated as pure entities but as historical, shifting and discursively produced concepts that are taken up by researchers in a variety of ways (Sandelowski, 2000, Kahlke, 2014).

Sandelowski (2000), postulated that this approach is very useful and recommended for researchers wanting to find answers to *what*, *who* and *where* questions. She further stressed that it is the method of choice when straight, in-depth descriptions of phenomena are desired in any piece of research (Sandelowski, 2000). It has also been established that when a little is known about a phenomenon, the best way is to explore and give a rich description and interpretation of that phenomenon (Converse, 2012). From the literature review, it is evident that the voices of mothers are mostly heard when studies of this nature were conducted in other settings and that of fathers were less, and the views of other family members were rarely reported. With little known about the voices of other significant family members, exploring, describing, and interpreting the experiences of these members was the most appropriate research endeavour hence making the generic methodology the method of choice for this study.

Proponents of the generic qualitative approach argue that this design has limitations pertaining to epistemological or theoretical void (i.e. most of these designs do not use an epistemology or theory to underpin their designs) and method slurring (where mixing methodologies may lead to contradictions between all elements of the research). They argue that theoretical void and method slurring raise an issue of congruence in a generic qualitative study (Kahlke, 2014, Merriam, 2002b, Sandelowski, 2000). However, proponents and adherents of the generic qualitative research have accounted for these pitfalls by proposing that in order to overcome the problem of theoretical void and method slurring, researchers using this design must underpin their studies with appropriate epistemologies, theories and methods (Kahlke, 2014, Sandelowski, 2000), stick to them throughout the research process and account for them in their study report. These pitfalls have also been accounted for in this study by a specified epistemology (pragmatism), theory (Frank's narrative typologies), methodology (generic qualitative) and method (interviews) and these were followed throughout the research process to establish congruence.

3.8 Methods

The methods of a study or research, from the standpoint definition of scholars, refer to the practical activities of the research and such practical activities include sampling, data collection and management, analysis of data and reporting of study findings (Carter and Little, 2007). This section will, therefore, demonstrate the various actions that were incorporated or involved in this research and will demonstrate the iterative nature of the study. The methods of this study will demonstrate the research process from the study design to the part of data collection, data management and analysis while integrating into it the fieldwork involved in the study to demonstrate how the study design emerged or occurred throughout the study. This will provide an audit trail for the process of sampling, data collection and data analysis.

3.8.1 The research context /study setting

The study was conducted at the child health department of the Komfo Anokye teaching hospital (KATH), located in Kumasi, the capital city of the Ashanti region, which provides Paediatric Services to all children within the Kumasi Metropolis and beyond. At the time of the study, the department was providing services to nearly 11,276 children as in-patients and 20,239 children as out-patients among which about 5000 children reported with cerebral palsy. This data suggests that about 14 children with cerebral palsy were being brought to the hospital to meet with a therapist every day.

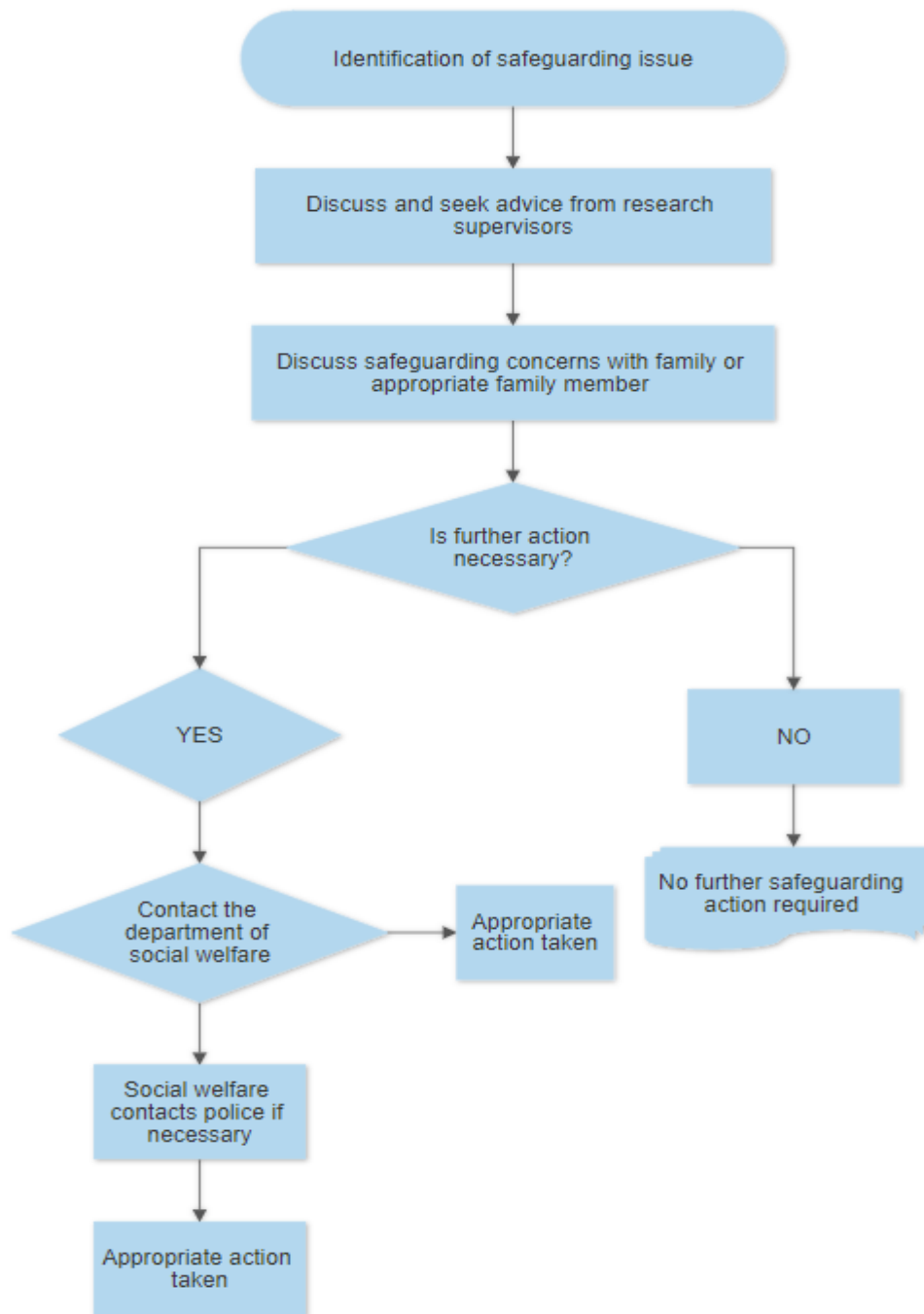
3.8.2 Ethical considerations

With regards to study subjects or interviewees, the general ethical principle in this study was to impose no harm. To ensure this outcome, this research was carried under the auspices of both the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee (FMHS REC) and that of the Komfo Anokye Teaching hospital (ethical approval at Appendix 1). Voluntary informed written consent (Appendix 2) was obtained from participants before interviews were conducted and participants were given the opportunity to decline or withdraw from the study at any time. Before the commencement of the interviews, participants were given information sheets (Appendix 3) which provided information regarding the research in a simple understandable language, i.e. the study overview, study aim, the data collection method (i.e. interviews, audio-recording), volunteering to participate and right of

refusal to participate at any stage. Permission was also sought before audio-recording the interviews to ensure that participants were comfortable with this process. Requiring extensive time from each family member was also an ethical concern that was addressed with them prior to data collection to ensure that they will be available for interviews at their own free will.

Furthermore, since this was a sensitive topic, it was anticipated that safeguarding issues may be disclosed during the interview process. For instance, disability experiences have been reported to include child abuse and neglect, and suicidal thoughts or risks (Hayes and Sloat, 1988, Rourke et al., 1989). Hence, prior to entering into the field, an appropriate local referral mechanism was developed for family members who may disclose safeguarding issues in order to seek help for them and their children. It was anticipated that if an issue arose that would require professional help, locally identified professionals would be contacted for such help. It was also anticipated that should an unexpected ethical concern arise in the process of data collection, locally identified professionals or consultants would be contacted to identify the appropriate means of handling such an issue. Figure 6 details the safeguarding steps that were anticipated to be taken should any safeguarding issues be raised during data collection.

Fig.6: flowchart showing safeguarding steps



Confidentiality was an important issue that was encountered in this study, especially when family members nominated significant others to participate in this study. It was very important for me to make the study subjects aware that issues that were discussed in one interview with a family member would be kept confidential and not shared with other family members. Furthermore, to ensure anonymity actual names were replaced with pseudonyms. Participants were informed about the fact that the results of the study would be published and shared in journals and conferences, but

they would be ensured of their anonymity and confidentiality while reporting study results. Data from participants were locked with a password on a computer.

3.8.3 Sampling strategy

Purposeful sampling was used to select participants for this study who were family members living with a child with cerebral palsy. This type of non-random sampling was used in this study because it increased the utility of information obtained, in that participants were more likely to possess knowledge and information about living with a child with cerebral palsy in the family (McMillan et al., 1993). It must be recognised that the sampling strategy used and the sample size should be governed by the methodology and the topic to be investigated (Higginbottom, 2004). The focus of this current study was to gain an in-depth exploration and understanding (Ritchie et al., 2013). The focus of sampling in qualitative studies is to reach the point of data saturation where information or data acquired becomes repetitive. Another focus of sampling in qualitative studies is 'information power'. Information power holds that, if a study is supported by a theory, has a strong interview dialogue, has a narrow study aim and the analysis includes a longitudinal in-depth exploration of narratives or details of discourse, the study will need fewer participants. On the other hand, a larger number of participants is needed when the study aim is broad, participant combination is less specific for the research question, there is a weak interview dialogue and if cross-case analysis is conducted, especially where the aim is to cover broad variations on a phenomenon (Malterud et al., 2015). This current study has a defined theory and proposed a strong interview dialogue and participant recruitment was more specific to family members living with children with cerebral palsy, which would mean a small sample was required to generate high information. Although decisions about specific sample sizes in this study were determined in response to the study progress, usually, generic qualitative studies with high information power and which achieved data saturation when studying similar individuals had a participant range from 30-60 (Malterud et al., 2015, Creswell, 2012). The sample size was therefore expected to fall within this range. Participant sampling in this research occurred in the year 2017 and it spanned across a period of 10 months (from February to November). The size of the sample was determined by the information power of the study as discussed in the study design section.

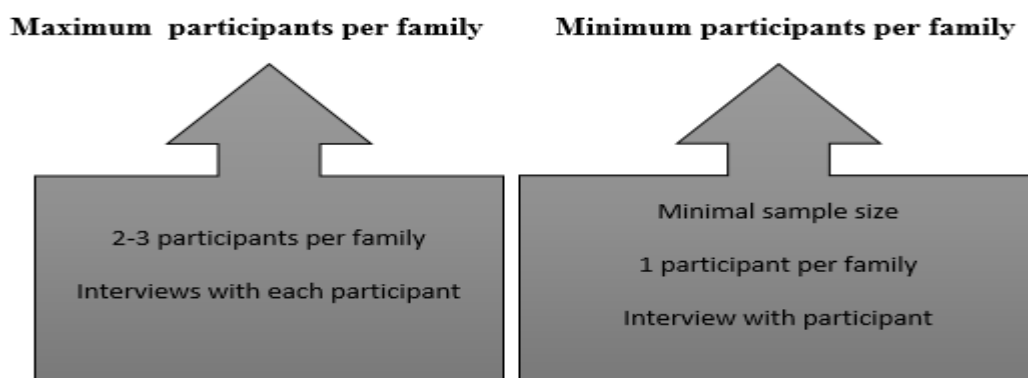
3.8.4 Inclusion criteria

For the purpose of this study, the term family means those individuals who are considered significant in the life of the child in either the nuclear or extended family of the child with CP.

- Family members that had children with cerebral palsy that came to the Child Health department were considered potential participants for this study.
- Family members of children with CP from ages 5-17 were considered for the study. It was expected that from age 5 years and above, the family member would have lived with the child long enough to be able to talk about experiences during diagnosis and during the growing milestones of the child. Again, the cut off age for Children with CP was 17 because in Ghana, it is considered that a person above age 17 is no longer a child (Constitution of Ghana, 1992)

Figure 7 shows that 2-3 participants, representing the maximum number of participants expected from a family were sought for this study but also there was the recognition that such a complex sample might not be achieved for all the families. Therefore, a provision was made for the minimal sample requirement which was one participant from a family.

Fig.7: Maximum versus minimum participants per family



3.8.5 Exclusion criteria

- Family members with children with CP below age 5 or above age 17 were excluded

- Family members aged below 17 were excluded
- Family members who did not come to the Komfo Anokye Hospital excluded

3.8.6 Recruitment process

Physiotherapists in the child health department at the Komfo Anokye Teaching hospital were provided with leaflets containing information on the study (Appendix 4). Posters advertising the study (Appendix 5) were displayed in patient waiting areas at the department. The study was introduced to 50 mothers at the monthly meeting of physiotherapists and family members. Contact information of mothers who expressed interest in the study was taken by the researcher. Those mothers who expressed an interest in taking part in the study were contacted by telephone to arrange an appointment to meet and discuss the study in more detail. Mothers who consented to take part in the study were recruited into the study. Arrangements were then made through the mothers for an opportunity to meet other family members to talk to them about the study and those who expressed interest were formally recruited. Arrangements were made afterward, for times and days suitable for participant interviews to be conducted.

3.8.7 Data collection method: semi-structured interviews

Pragmatists adhere to the fact that language and communication are the best means to explore people's experiences (Oquist, 1978). This assumption has therefore informed the choice of using interviews to explore the experiences of family members having children diagnosed with cerebral palsy. Interviews allow investigators to access people's perceptions, feelings, ideas and memories and rely on participants' language in order to give voice to their experiences. Furthermore, interviews are purposeful conversations that allow researchers to collect descriptive data from study subjects, enabling them to gain insights into the participants' worlds (Reinharz and Davidman, 1992). Semi-structured interviews assume that questions must be comprehensible to interviewees while interviewers must respond to participants in order to understand their world at the same time (Qu and Dumay, 2011). Apart from providing structure to the questions and interview format, semi-structured interviews also provide flexibility to probe issues participants may raise (Glesne, 2014). The use of open-ended questions ensures the collection of rich data by providing the opportunity to describe

their experiences in detail. Prompts are used when needed to clarify the meaning of responses and to encourage in-depth descriptions (Moustakas, 1994).

Semistructured face-to-face interviews were used in exploring the experiences of family members who were involved in the study. However, these semi-structured interviews were used as a guide (Appendix 6) and questions were allowed to evolve during the interview process. From the existing literature of living with children with cerebral palsy and from my own clinical experience gained through encounters with some of these family members, the development of an interview guide became possible. Pragmatism, the epistemological position of this research places emphasis on the interaction between the researcher and the researched. Therefore with regards to this, interviews were regarded as events where the interviewer and the interviewee participated actively. Interviews were conducted in such a way that study participants were able to recall, interact and verbalize (Diver et al., 2013b, Karnieli-Miller et al., 2009) whiles doing this, I was also careful to consider my relationship with each interviewee in such a way that would enable them to open up more about their experiences in order to influence the quality of the data that would be obtained. So to ensure a good participant-researcher relationship, a rapport was built with participants through telephone calls and interviews during the initial stages of the research and this was essential as it assisted in gaining access to individual stories of participants. I also ensured that participants were allowed to choose their own venue, and to be interviewed at their own time schedule.

Broad open-ended questions were used during interviews and this was aimed at generating responses that would describe participants' experiences in detail. The face-to-face interviews conducted during data collection provided the grounds for clarifying or expanding the thoughts of participants (Speziale et al., 2011). At the initial stages of the interview, my background as a researcher with less research experience was a challenge and brought some nervousness with regards to being able to conduct adequate interviews. However, critiques on the initial interviews by my supervisors and the progression of the subsequent interviews shrank the nervousness and made it less of a concern. Research has made it evident, how power differences between the researcher and the researched can influence the amount and quality of information that would be given by participants during a study (Karnieli-Miller et al., 2009). Before the commencement of this research, I worked as a full-time rehabilitation officer in a

hospital. However, during the time of the interview, I had terminated this job and was a full-time Ph.D. student. Decisions were therefore made for them to know that I was a Ph.D. student who was trying to find out how it is to live with a child with cerebral palsy. My role was, therefore, a researcher and not a rehabilitation officer and I made this clear to the study participants, although I disclosed my professional background to them.

Data was also collected, in the form of field notes and demographic information, in addition to the interview. The field notes that were recorded during participant interviews included a description of the premise or context where the interviews took place and demographic information about participants. The collection of demographic data was aimed at describing the characteristics of the study sample. Field notes and demographic characteristics informed the writing of contextual backgrounds for study participants as depicted in the participant demographics chapter (i.e. chapter 4) All interviews were conducted in the most popular tongue in Ghana, Twi, and were later transcribed and translated to English. In all, 30 family members were interviewed in this study

3.8.8 Conduction of interviews

Before the interviews began, all participants had the choice to select a venue where they would be convenient for an interview (whether at the hospital, at home or any other place of convenience) and all of them chose to be interviewed at home. Interviews lasted between 60 minutes and 120 minutes. In order to build rapport with the participants, each interview session began with non-recorded conversations enquiring about their day, the health and wellbeing of the child with CP. I would also repeat the purpose of the interviews with them during such unrecorded sessions. Prior to the start of the recorded interviews, participants were reminded that they did not have to discuss anything they felt uneasy about, were free to discontinue the interview at any point they wanted and were encouraged to take breaks when they wanted to. Reflections were made after each interview in relation to how the interviews were proceeding to find out areas that needed more improvement and areas that needed to be explored further in subsequent interviews. Online discussions with my supervisors further assessed how the interviews were progressing and we discussed areas that needed to be improved, probed or explored more and also questions that needed to

be refined or polished. These reflections were always kept as part of my research diary.

3.8.9 Data analysis

It is important to reiterate that guidelines for qualitative data analysis are not rules and following basic precepts of pragmatism, the choice of analysis must be applied flexibly to fit the research question and data. Furthermore, the analysis of data is not a linear process of simply moving from one phase to the next. Instead, it is a more recursive process, where movement is back and forth as needed, throughout the phases (Patton, 1990). Data in the current study were analysed in two ways:

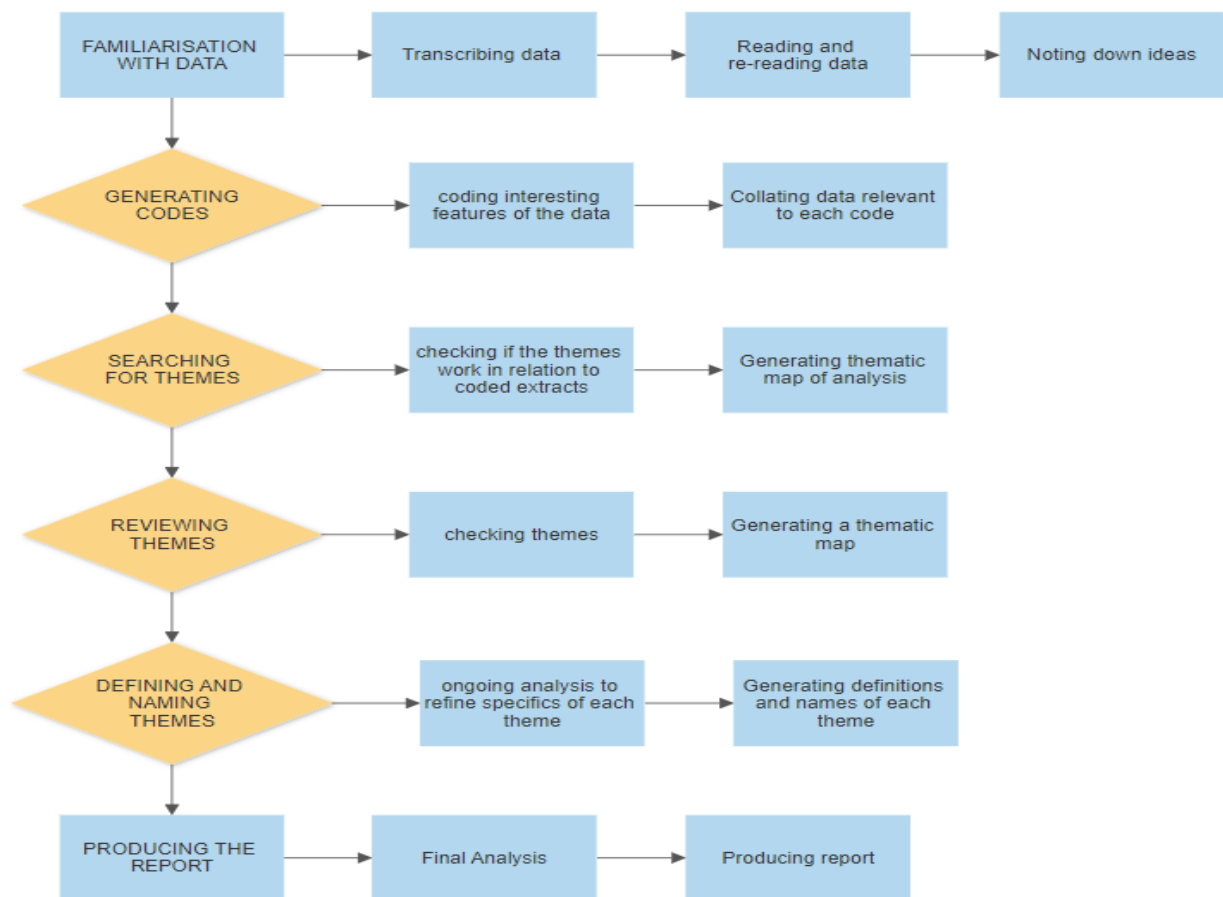
- 1) Thematic analysis
- 2) Narrative thematic analysis (thematic analysis evolved to narrative thematic analysis)

The next sections will present or demonstrate the two data analysis processes as they occurred in this study

3.8.9.1 The thematic analysis process

Data analysis in this study was approached initially by the utilisation of thematic analysis (Braun and Clarke, 2006). After the transcription of data into verbatim notes, proper data analysis began by first using the thematic analysis approach. Thematic analysis in this study was done with NVivo, a qualitative data analysis software, underpinned by Braun and Clarke's six-phase approach to thematic analysis (Braun and Clarke, 2012) as displayed diagrammatically in fig 8. Thematic analysis was done in NVivo as the first phase of analysis in this study to systematically identify, organise, and offer insight into patterns of meaning across the data sets (Braun and Clarke, 2012). During the thematic analysis process, the researcher was conscious and had a growing interest in the experience and meanings attached to having a child with cerebral palsy in the family. Figure 8 demonstrates the thematic analysis process as proposed by Braun and Clarke (2012). These steps would be explained below to elucidate how the themes in this study were arrived at.

Fig. 8: The thematic analysis process, Braun and Clarke (2012)



Familiarisation with data

Familiarisation with data involves the act of immersing oneself in the data through transcription reading and re-reading textual data or transcribed documents or listening to the audio recordings again (Braun and Clarke, 2012). I familiarised myself with data through transcription, reading and re-reading of data and some preliminary data analysis was done in the form of reflections, in-depth exploration through listening back to interviews and critiques on interview transcripts before the actual data analysis proper. All interviews were conducted in Twi and were later transcribed and translated to English. The translated interviews were then back-translated to Twi by local professional translation services to ensure that meaning had not been lost. The use of a professional translation service also provided rigor to the transcription and translation process. Translated interview transcripts were then sent to supervisors for thorough reading, critiques and feedback. Feedbacks included discussions about areas which needed more probing or needed further exploration, questions which

needed to be reframed, etc. and the appropriate changes were made. Data transcription started in Ghana and ended in Nottingham. The transcribing of interviews provided the opportunity to familiarize with data through listening to the recordings over and over again and through reading and re-reading transcripts

Generating Initial codes

The process of assigning a word or a phrase to symbolically represent the portion of data, called coding, is a crucial aspect of data analysis because it represents and captures the primary content and essence of a datum (Basil, 2003, Saldaña, 2015). Apart from representing a label, coding also serves as a link that leads the researcher from the data to the discovery of an idea and from that idea to all portions of the data pertaining to the idea (Richards and Morse, 2012). Coding helps in the organisation and grouping of similarly coded data into categories based on the similar characteristics they share. Inductive coding was used to conduct the process of thematic analysis. This means that coding and theme formation were directed by the data content obtained from the semi-structured interviews conducted in this study. Initial reading was not informed by any theoretical framework but the data was taken as the sole source of meaning derivation. The analysis was thus performed rooted in data (Braun and Clarke, 2012). The use of an inductive coding process allowed the objective scrutiny of data, preventing the conscious application of themes from previous literature and made the researcher opened to the emergence of themes (Boyatzis, 1998). Coding in this study initially began by hard-copy coding, where coding was done on a sheet of paper on two interviews before all data was transferred into Nvivo for coding. The initial codes generated on a piece of paper were cross-checked by the second supervisor (Dr Claire Diver). This was done through a two-way coding comparison process in which the researcher and supervisor developed initial codes on two interview sets and the researcher's code was compared to that of the supervisor. All subsequent coding was done by the researcher in NVivo. In NVivo, data sets were organised into fathers, mothers, siblings and extended family and each data set was coded separately. This was done with the focus of detecting or bringing out differences between participant groups, as this was one of the objectives of this study. Code-generation involved succinct and self-explanatory labels (called nodes in Nvivo) which were used to identify important features of the data. Coding of the entire data set was done through descriptive codes which were labelled and briefly

described. Segments of texts which were coded more than once, were revised and duplicate codes were merged and redefined. The process of revising, redefining and merging codes was tedious and intensive as the researcher had to go back and forth through the data sets to finalise descriptive codes and more time was required to make such changes.

Searching for themes and reviewing themes

The third and fourth stages of thematic analysis, *searching for themes* and *reviewing themes* were done together. The next step after coding participants' data was to organise codes into categories for each participant group, and further put these categories into themes which required "hitting categories with one another" (Morse, 1994) to develop a coherent synthesis of organised codes and reviewing these into themes. The entire datasets containing codes were considered again by the researcher after some days with the focus of revising and rearranging the original codes. Interpretive codes were formed by merging descriptive codes which appeared to express similar meaning. This was done by using NVivo's function of *new nodes* where new codes, called "parent nodes" could be formed and "child nodes" would be ranked under them. Therefore, in this way, interpretive codes were formed in Nvivo as *parent nodes* and descriptive codes were organised under them as *child nodes*. Concepts developed began relating to each other and a hierarchy of descriptive codes was created. The application of interpretive codes was still inductive and was devoid of any theoretical concepts. As the application of interpretive codes progressed, some of the interpretive codes also became repetitive and these were merged together. A collation of coded interpretive data was done and a long but exhaustive list of codes was realised and these were organised into themes and sub-themes. Coded interpretive data for each participant group was categorized and meanings were attributed to them by putting them into themes and sub-themes. Themes were also checked to ascertain whether they worked with the coded data.

Defining and naming themes

At this stage, all thematic groupings were considered again and reworked. This was done by looking back at all the codes which were developed in the initial stages which formed part of the themes and sub-themes. This was to enhance analytical rigour and credibility of study findings. At this stage, some sub-themes were merged to form themes and broad overarching themes were identified that expressed a central concept consisting of a few smaller themes and sub-themes. The final step involved naming the respective themes and sub-themes so that these names would reflect the original data (Boyatzis, 1998). Three broad themes were developed under thematic analysis for all participants and these themes were *Help-Seeking Behaviour*, *Cultural and Religious Beliefs about Cerebral Palsy*, and the *Personal Impact of Cerebral Palsy*.

Writing a thematic analysis report

The last stage in the thematic analysis was to report the analytical findings. After data analysis, it was evident that the information shared by all participants in the different heterogeneous groups (fathers, mothers, siblings and extended family) was similar in content and themes except for some nuances and complexities. It was therefore agreed after further discussion at supervision meeting, to present the results for all participants together and where there existed some nuances or complexities, they would be highlighted. However, after writing on the themes from thematic analysis, interpretations appeared to be superficial upon discussion at a supervision meeting and the themes struggled to elucidate the depth required. At this stage, it was evident that the analytic process adopted still remained at a descriptive level as opposed to developing a theoretical understanding of the data and also the findings mostly reflected the existing literature on living with children with cerebral palsy in the family. Transitioning from description to a thorough explanation level and for that matter, theory generation, became difficult. Thematic analysis has been argued by some researchers not to be used as a separated method of analysis but rather as an aid to other qualitative analysis methods as it may not provide the depth and interpretation required (Boyatzis, 1998, Holloway and Todres, 2003, Ryan and Bernard, 2000) and this appeared to be manifested in the thematic results generated.

3.8.9.2 Narrative thematic analysis

Findings from the thematic analysis of data failed to explain the meaning attached to having a child with cerebral palsy in the family and also struggled to provide a useful model or framework that could enhance the understanding of living with a child with cerebral palsy in the family. Diver et.al (2013) reported the results of a generic qualitative study that utilised illness narratives underpinned by the narrative typologies described by Frank (1995). Diver et.al (2013) described and interpreted how individuals diagnosed with Fibromyalgia syndrome make sense or attached meaning to their condition. I happened to get acquainted with this study, as the principal researcher was one of my supervisors. The study shared some similarities with my own as it was exploring the illness experience of a complex chronic condition and also utilised a generic qualitative methodology and qualitative interviews. It also shared the same philosophical stance with my study. In contrast however, the study was conducted on ill persons themselves and not their family members. The philosophical and methodological commitments, and the findings of the study appeared to resonate with my understanding and beliefs of what was emerging from the study data. At this stage, the researcher was led to examine the potential usefulness of illness narratives and for that matter, Frank's (1995) narrative typologies in enhancing the understanding and theoretical interpretation of the study findings that had emerged from thematic analysis. The more I gained insight into Frank's narrative typologies, the data I had coded into themes through thematic analysis, began making sense and a new depth of explanations were revealed. For instance, I saw through the themes organised in thematic analysis that there was a continuum between the themes developed demonstrating a beginning, a middle and an end. It also appeared that the stories of participants reflected a kaleidoscope effect in which there was the emergence of different experiential moments at different points of their stories with one experiential moment assuming the foreground position when other moments were relegated to the background. Narrative thematic analysis was therefore done deductively in Nvivo, to provide an in-depth and enhanced interpretation to the experience of living with children with cerebral palsy, by deductively reorganizing the themes developed through thematic analysis, in light of Arthur Frank's narrative typologies, using the themes developed from thematic analysis to underpin each narrative type. It appeared that each narrative appeared to exhibit core characteristics that were evident within each theme developed from thematic analysis. Therefore, *the restitution narrative* of

participants in this study was underpinned by *help-seeking behaviour and some religious beliefs* (belief in God for cure), *the chaos narrative* was underpinned by *the personal impact of cerebral palsy and cultural beliefs*, and the quest narrative was *underpinned by religious beliefs*. These will be presented in three results chapters to demonstrate how participants enacted restitution, chaos and quest narratives in their experiences of living with children with cerebral palsy. Second member checking was also done by the supervision team by cross-checking the themes generated with data to ensure that data analysis was conducted correctly and that themes and findings generated were authentic. A synthesis of the results has been done in chapter 8 to pull together all the study findings and to highlight the subtle nuances that occurred within participant narratives. Frank's typologies, therefore, influenced the study results that have been reported in chapters five, six and seven. An exposition on Frank's narrative typologies has been given in section 3.7 in this chapter.

It is worth mentioning, that the current study did not intend to use a narrative approach. However, it was considered by the researcher that the emergent findings provided the opportunity to capture data that reflected this. It appeared the interviews conducted allowed participants to tell their stories in their own words and in the order in which they wanted to tell these stories. The study findings present a contrast to narrative approaches that start by asking people to tell their stories about an event (Diver et al., 2013a). However, the questions asked had facilitated a conversational flow and had disclosed what was important for study participants rather than an ordered strict list of questions to be followed.

Narrative analysis has gained the recognition as a means of understanding people's experiences through researcher and participant collaborations and through "*living and telling, reliving and retelling, the stories of the experiences that made up people's lives, both individual and social*" (Clandinin and Connelly, 2000, p.20, Holloway and Fresh Water, 2007). Not only does narrative analysis aim to identify individual experiences but it also tries to understand these experiences through the wider social and cultural narratives within which these experiences are formed, through communicating with individuals and also through writing and interpretation (Clandinin and Rosiek, 2007). It was the aim of this research to explore the experiences of living with children with cerebral palsy through multiple perspectives of primary stakeholders. The narrative analysis appears to support the aim of this study given its focus on the experiences of

individuals in relation to the social and cultural context within which these individuals function and also a focus on re-storying their life experiences. Narrative analysis does not seek to identify a single “truth or historical facts involved in participant experiences, a tenet which is commensurate with the Pragmatist philosophical underpinning of this research (Sandilowski, 1991). Additionally, narrative analysis renders a recognition to the temporality and the transient nature of truth, which also resonates with the pragmatist perspective of this research.

Narrative analysis also seeks to understand how individuals construct meaning from their experiences through storytelling, striving for a coherence theory of truth rather than a correspondent theory of truth. Some scholars argue that both multiple and conflicting narratives can be organised together and analysis could be presented from them, rather than focusing on a single perspective, and this also reflects the intentions of this study (Holloway and Freshwater, 2007). Doing narrative thematic analysis in this study was aimed at providing an enhanced understanding around living with children with cerebral palsy (Patsiopoulos and Buchanan, 2011) since existing literature had mainly focused on thematic analysis. It is anticipated that narrative analysis could provide a different level of understanding of the experience of living with children with cerebral palsy in the family. Furthermore, it would enable the audience to know more about the cerebral palsy narrative to inform reflective practice as this is non-existent in literature (Patsiopoulos and Buchanan, 2011).

3.9 Establishing rigour

In order to give a convincing account, clear and accurate records were kept and a detailed description of the research process (audit trail) has been reported (Cooper and Endacott, 2007) in both the methods section and reflexivity chapter. This has provided an audit trail that will enable readers to consider the extent of generalization of findings of this research and their relevance in other settings. In addition, to enhance the reliability and validity of research findings, all perspectives from participants in the study were considered for analysis so as to ensure fair dealing. (Mays and Pope, 2000b)

3.10 Reflexivity: Epistemological and methodological positioning

Reflexivity in epistemology and methodology implies the recognition that choosing a particular epistemology and methodology is not an arbitrary decision but rather is based on the reality they aim to uncover. Scholars (Guba and Lincoln, 1994) therefore, make the suggestion that the choice of a method of investigation, must be located within an enquiry paradigm, which they defined as the “basic belief system or world view that guides the investigator, not only in the choice of methods but in ontologically and epistemologically fundamental ways ” (Lincoln and Guba,1994, p.105). In terms of reflexivity in this chapter, I have traced how the choice of my epistemological (pragmatism), methodological (generic qualitative) and methods (semi-structured interviews) leaning, affected this research. Pragmatism, my epistemological position, became evident after a review of the literature. I discovered after the literature review that the experiences and views of the mothers have mostly constituted and represented the truth of the experience of living with cerebral palsy. I wanted to challenge the existing truth as I had already accepted the philosophical ideology and the reality that truth changes from time to time and this truth may vary according to individual experiences. I believed the experiences of living with children having cerebral palsy, mostly constructed with the views of mothers, as the important truth or almost absolute truth, was biased. This could change or could be broadened should the experiences of more significant members in the family like fathers, extended family and siblings be explored, and that this could represent a whole new truth of living with children in the family. Pragmatism, therefore, lent itself as the appropriate philosophy for this study.

The position of the methodological paradigm for this study, the qualitative paradigm, also became evident after the research question was formulated (i.e.what are the experiences of families with children diagnosed with cerebral palsy?). As the research question and the objectives of the study centred on the experiences of family members, the study lent itself to the qualitative paradigm. It also became evident, and I was also more confident, that the generic qualitative methodology from the qualitative paradigm would be more appropriate for this investigation as its tenets also align with the pragmatist epistemology (choosing the right tool for the right job). As someone who was more used to and mainly engaged with the quantitative paradigm at first and second degree level, I found it exciting to do a qualitative study this time around.

I believed that it would add to and broaden my research knowledge base because I would gain a valuable experience in conducting research in both paradigms.

The research method, semi-structured interview, was also adopted after a review of the literature. Initially, I had wanted to explore the experiences of participants through unstructured interviews. As a naive qualitative researcher at that time, I felt I needed some guide if I would be able to conduct successful interviews that would generate in-depth data. I considered that using the knowledge gained from the literature review on the experiences of living with children with cerebral palsy in the family and the knowledge gained from my own consultations with children with cerebral palsy and their families, could help me to formulate questions that could explore the experiences of family members from the known to the unknown. During the fieldwork, as my confidence increased, I was able to probe into the experiences of participants and it felt as if the structured questions had metamorphosed into unstructured questions.

3.10.1 Positional reflexivity: insider and outsider status

Positional reflexivity pertains to the autobiographical, critical examination and the articulation of the position of researchers in the world they study (Macbeth, 2001). Douglas Macbeth, writing on reflexivity in qualitative research, gave an elaboration of positional reflexivity as he stated:

“Positional reflexivity takes up the analysts’ (uncertain) position and positioning in the world he or she studies and is often expressed with a vigilance for unseen, privileged, or, worse, exploitative relationships between analyst and the world.....Reflexivity leads the analyst to take up the knots of place and biography and to deconstruct the dualities of power and anti-power, hegemony and resistance, and insider and outsider to reveal and describe how our representations of the world and those who live there are indeed positionally organized” (Macbeth, 2001, p.38)

My comprehension of positional reflexivity would be to identify how some aspects of my identity could have influenced how the current study was conducted. The identification of how a researcher’s identity affects or influences the research process is known to be a-not-straightforward matter. It has been suggested that knowing oneself with sure certainty is impossible because humans could simultaneously

express multiple identities and the determination of which identity is relevant in a particular situation is just a matter of judgment (Parker, 2014). However, it has been considered that the self-identity of researchers, their beliefs and standards have an impact or influence on how the study is designed and interpreted (Carter and Little, 2007)

In the qualitative research process, the differences and similarities between the researcher and the researched with regards to social markers such as ethnicity, sexuality, gender, class, race, etc are considered very important (Mauthner and Doucet, 2003). Therefore, a researcher belonging to the same group in which their participants also belong, with respect to these social markers, can be classified as an insider and a researcher is considered an outsider when they do not necessarily share similar social characteristics with study subjects (Hayfield and Huxley, 2015). The identification of a researcher's position as an outsider/ insider is deemed essential as it is considered an epistemological matter, as it has been argued that comparing the researcher's position with his participants can impact directly on the knowledge being constructed between the two (Berger, 2015, Dwyer et al., 2008, Griffith, 1998, Watts, 2006). Hayfield and Huxley (2015) further intimated that a researcher who positions themselves as an insider tends to have an advantage in the research process as compared to the outsider, particularly in disclosing their position to study subjects. However, other researchers (Bridges, 2001, Horowitz, 1986) have offered a contrary opinion, arguing that researchers who enter the field as outsiders have more advantages as they are in good stead to make observations and draw conclusions that insiders could not have detected or overlooked. However, studies that have engaged joint researcher positions, employing the use of both insider and outsider perspectives (Berger, 2015, Hayfield and Huxley, 2015), argue that no matter what the researchers position may be, what is most important is giving a clear account on how these positions could or might have influenced/impacted the research process. Therefore, in the current study, I positioned as both an insider and an outsider: I played a role in both describing and presenting the experiences of family members with children diagnosed with cerebral palsy, although the insider status dominated. The next sections highlights the insider and outsider status adopted in the research process.

3.10.1.1 The insider status

My insider status as a health professional helped me gain easy access to the study site as I had work contacts at the hospital already. For example, my master's degree supervisor was the head of the child health clinic where the physiotherapy unit was sited and I had already established connections with most of these therapists through professional engagements, even before the research topic came to mind. As an insider, I approached study participants with some knowledge around cultural and social issues about disability in Ghana and also an insight about the study topic from the existing literature which might have influenced the data collection and analysis. I disclosed my identity to study participants as a Ph.D. student studying in the UK, at the University of Nottingham, and who previously worked as a rehabilitation therapist with adults and children with disabilities at a hospital in Ghana; this reinforced my insider position. The disclosure of my professional identity might have made them consider me as an expert in dealing with children with disabilities, and could have helped in eliciting important information from study participants. This was evident in interview 4 after the interview had ended: I wrote this in my reflexive diary after I left that participant's house.

This participant felt that sharing her information with me was worth it as she does not open up to anybody at all. I feel that disclosing my professional background has helped in making the participant confide in me, sharing experiences which she deemed valuable....Researcher

Furthermore, being a national of the country in which the study was conducted strengthened my position as an insider: I was an inhabitant in the region in which the study was sited, spoke the same language and was part of the same cultural and religious heritage. I felt these insider characteristics enhanced the building of rapport with study participants, might have made them feel comfortable around me and this could have encouraged them to share their experiences with ease. I was able to understand and clarify the use of contextual words such as “*nsuoba*” (*child from the river*) . I believe if I was from a different culture, I would have missed on understanding the use of such contextual words. Again, due to respondents' assumption of similar shared characteristics, there was often the use of words like “you”, “we”, “us” “we ” “our” and I felt I was being involved or included in such descriptions.

My insider status also made navigating to participant homes to conduct the interviews very easy, as I knew my way around the city in which the study was conducted. Furthermore, it might have taken an outsider researcher quite a long time to find out what constituted culturally appropriate behaviour, speech and dress, as these are deemed very important in the Ghanaian society; these are the lenses through which people can be judged and could determine whether they would relate well to you or not. I felt I was able to present myself appropriately from the outset.

A disadvantage of being an insider researcher is that there is the danger of “overfamiliarity” to an extent that it could influence the researcher taking things for granted during interviews or data collection (Bridges, 2001, Horowitz, 1986, Kanuha, 2000). Being aware of this, I asked increasingly open questions, recording what was said in an interview and inquiring from participants if they had wanted to share some information I had not asked about. In this way, I felt that I had elicited and captured the important information from participants and had not overlooked or missed out on any information that participants wanted to share.

3.10.1.2 The outsider status

In this study, I also exhibited some characteristics of an outsider. Within this study, I had no personal experience of living with a child diagnosed with cerebral palsy in my family. It has been argued that when a researcher has personal experience of the phenomenon being researched, it is likely to end in generating an unfavourable research result or outcome due to the difficulty in detaching one’s own self from their experience and also a lack of objectivity could arise. Therefore, it was from a point of neutrality that I questioned participants to get acquainted with their experiences. I believe this helped provide deep probing and insight.

Though I had worked as a rehabilitation therapist and encountered some parents living with children with cerebral palsy, I had never met any of the participants involved in this study before; they were recruited from a different hospital to where I had worked. The participants, therefore, had no previous connections with me, and this helped characterise my participation as an outsider. At the outset I was unsure how participants would respond due to their unfamiliarity with me and this made me feel uneasy. My uneasiness was substantiated when I was trying to contact one mother for an interview. This mother had scheduled a date, time and venue to be interviewed.

On this day, I made numerous calls to this mother for confirmation but she didn't respond. Later in the evening, she called to tell me she had to travel to another city and wouldn't know when she would be back. I had to disappointingly cancel the interview and delete her name from the interview list. One father also dropped from the interview, after scheduled an appointment: he told me he was a taxi driver and doubted he could ever get time for the interview. I contemplated whether I would get enough data in time to return to Nottingham from Ghana as I felt participant involvement was unpredictable. However, no further occurrences of this nature took place.

Another criterion that characterised me as an outsider, was my educational status. Almost all of the participants involved in this study, except two, had no formal education. In contrast I had a very high academic status (Ph.D. student): I initially had concerns that my own educational status might influence how study participants would relate to me and what information they might be willing to share. Within Ghanaian culture people who have higher educational attainments are accorded a great amount of respect and dignity. I witnessed this in how some participants would offer to bring out the best sofa chairs from their living rooms to me before the commencement of interviews: I considered how this could influence how participants might relate to me and would decline and ask for one of the ordinary wooden chairs. I felt that this could mitigate the influence of power within the participant researcher relationship and compelled participants to open up more to me. Some participants, after the interview, would remark that despite my high educational status, I was a humble person and they felt comfortable talking with me. Others would remark that it was an honour for a person with a very high educational status to have visited their abode, had talked with them and expressed how pleased they were. Such remarks made me feel that I had not used my power to coerce, exploit or prevent study participants from sharing information with me.

3.10.2 Reflections on data collection

As stated previously, my previous position as a disability and rehabilitation practitioner influenced the access I gained to study participants quicker than I had anticipated. I was invited to talk about my study during a monthly meeting of physiotherapists and family members and was a good platform as many mothers came with their children.

Mothers expressed interest in the study and provided their contact: afterwards I called them, and then went to their houses individually and consented them to the study. I used these mothers as gatekeepers to reach other members in the family who also consented to study participation.

After each interview, I recorded my thoughts and reflections in my researcher diary, so as to stay reflective throughout the study. This would normally take place immediately and generally centred on: how well the interview was conducted, where I thought I could have explored further, and emerging areas that called for exploration. Whilst conducting interviews, I was conscious that some safeguarding issues could arise from the interviews that would need to be addressed, but this was not the case.

This study enhanced my experience in doing research interviews. Allowing participants to share what was relevant to them was the focus or the emphasis on the interviews. However, as the interviews commenced, I felt participants veered off or detoured from the questions in the interview guide and I found myself trying to bring them back to the question. I was focused on getting them to say what I wanted to hear based on the interview guide; upon careful consideration and discussion with supervisors, after the first 2 interviews, I felt that there were pieces of information that participants wanted to share that I had not considered. An example was when they started bringing in the notion of superstition, spiritualism, mystery and religious beliefs into their experiences of living with children with cerebral palsy. Being a health professional who does not believe that the supernatural has a part to play in illness conditions, I did not include this in the initial interview guide and I decided I would allow participants to take me in this direction. Participants talked about religion and the supernatural in the subsequent interviews and it was interesting that a significant part of the views of all participants, centred on the supernatural and religion. I wrote a reflection on this development in my researcher diary:

“it appears a very significant part of participant experiences centres on religion and supernatural beliefs. Initially, I was hesitant in allowing participants to go this direction but it appears I made a good decision in allowing them to share their beliefs in religion and supernatural with regards to having a child with cerebral palsy because almost every participant is talking about these in their interviews. I would have lost a good chunk of

important and interesting data if I had resisted participants from sharing these beliefs. It is interesting the direction this study is taking"researcher

I gained confidence in facilitating participants telling me what they wanted to convinced that it could lead to yielding important data.

3.11 Conclusion

This chapter has demonstrated the epistemology, methodology, theoretical framework and methods employed in this study. It has demonstrated how the anticipated research actions were taken during the actual fieldwork and how reflexivity has informed the process.

CHAPTER FOUR: PARTICIPANT CONTEXTS AND DEMOGRAPHICS

4.1 Introduction

The presentation of participants' demographic characteristics when reporting any type of research or presenting research findings, has gained increasing attention over the years (Hammer, 2011). The need to provide specific participant information or characteristics including their racial/ ethnic group membership and socioeconomic status has been highlighted in literature (Ellis, 2009, Hammer, 2011). It has been argued that at a minimum, information about participants' age, their gender, race/ethnicity, socioeconomic status, level of education, and spoken languages must be provided when writing research reports (Hammer, 2011). However, pertinent to specific investigations, researchers are allowed to add additional information to these minimum participant demographic characteristics (Hammer, 2011). Presenting a thorough description about the demographics and contextual backgrounds of participants put researchers and readers in good stead to determine to whom study results or findings could be generalized, and also allows easy cross-comparisons to be made when studies are replicated (Beins, 2017). When demographic information of participants is excluded in research results, researchers "risk assuming the stance of absolutism, which assumes that the phenomena of interest are the same regardless of culture, race, ethnicity and socioeconomic status" (Hammer, 2011, p. 261). However, providing detailed demographic characteristics moves researchers to accept universalism, which recognises that "there may be universal psychological processes but that they manifest differently depending on the particular culture" (Beins, 2017, p. 341). This chapter will, therefore, present demographic information and contextual characteristics of all participants who took part in this study. This description of the context of each participant was developed from the audio recordings and field notes documented during the study period. Other important demographics of participants can be found in table 9 below. To ensure confidentiality and anonymity with regards to the identity of participants, all study subjects have been assigned with pseudonyms.

Table 9: Participant demographics

Participant pseudonym	Age (years)	Relationship to child	Marital status	Education level	Occupation	Religion
Abraham	60	Father	Married	None	Cloth weaver	Christian
Arthur	34	Father	Married	None	Butcher	Muslim
Duncan	45	Father	Married	None	Pastor	Christian
Kennedy	34	Father	Married	Master's	High School Teacher / Pastor	Christian
Nelson	36	Father	Married	None	Second-hand Clothes Seller	Christian
Norman	47	Father	Married	None	Butcher	Muslim
Betty	37	Mother	Cohabiting	None	Bar	Christian
Ernestina	36	Mother	Married	None	Second-hand Bags Seller	Christian
Florence	34	Mother	Married	None	Food Vendor	Muslim
Hannah	40	Mother	Married	None	Farmer	Christian
Harriet	29	Mother	Married	Master's	High School	Christian
Lydia	34	Mother	Married	None	Food Vendor	Christian
Nancy	40	Mother	Married	None	Food Vendor	Muslim
Lizzy	36	Mother	Married	None	Food Vendor	Christian
Nora	39	Mother	Married	None	Food Vendor	Christian
Debora	33	Mother	Married	None	Trader	Christian
Emilia	65	Grandmother	Married	None	Trader	Christian
Margaret	59	Grandmother	Widow	None	Restaurant Operator	Christian
Mary	60	Grandmother	Widow	None	Farmer	Traditionalist
Maud	38	Aunt	Married	None	Child	Christian
Natasha	62	Grandmother	Married	None	Grocery	Christian
Peter	73	Grandfather	Married	Diploma	Retired	Christian
Portia	40	Aunt	Married	None	Trader	Christian
Samson	50	Grandfather	Married	Certificate	Pastor	Christian
Fanny	18	Sister	Single	Studying	Student	Christian
Leah	23	Sister	Single	Diploma	Nurse	Christian
Lisa	18	Sister	Single	Studying	Student	Christian
Mildred	19	Sister	Single	Studying	Student	Christian
Rita	26	Sister	Married		Caterer	Christian
Rudolf	19	Brother	Single	Studying	Student	Muslim

4.2 The participants

This section will detail the broad family contexts of parents and significant others (siblings and extended family members) involved in the child with cerebral palsy's life that gave consent to be involved in this study.

Thirty (30) family members were recruited for this study and these could be divided into four significant groups: Mothers, Fathers, siblings and extended family. Data analysis, therefore, was based on the interviews from these four diverse groups, i.e. Mothers (10), Fathers (6), Siblings (6) and Extended family (8). Their ages ranged from 18 to 73 years. 22 were married, 2 were widows, 5 were not married and 1 was in a cohabiting relationship. The majority (25) were Christians, 4 were Muslims and 1 participant practised the traditional religion. All participants lived with one child with severe cerebral palsy in the family and their experiences centred around these children.

The contextual characteristics presented in this section will demonstrate each family context and how the family members relate to the child with cerebral palsy. The pragmatist philosophy employed in this study and the generic qualitative methodology, allows that the right means must be used in the construction of knowledge so as to enhance the understanding of data and results (Cooper and Endacott, 2007). Based on this understanding, it became evident that presenting the family contexts about participants in this section would be expedient as it would better enable readers to grasp the contextual characteristics associated with study participants against presenting only a table of demographics. Therefore, a presentation on the characteristics of members presented within each family and their relationship with the child with cerebral palsy and a short narration on how each child in the family developed cerebral palsy are demonstrated in the following sections. For reference purposes, the children in the family have also been represented by Pseudonyms.

4.2.1 Family 1

Child with CP	Alexander	6 years 5 months	Male
Ernestina		Mother	
Fanny		Sister	
Samson		Grandfather	

In the first family, three participants, Ernestina (mother), Fanny (sister) and Samson (grandfather), live with Alexander, a child with severe cerebral palsy who was 6 years 5 months old at the time of the interview. Ernestina and Fanny live with Alexander in the same compound house (a roundly built house with about 20 tenants sharing the same compound and toilet facilities) while his grandfather, Samson, lives separately but closely to their house. Ernestina is 36 years old, married but does not live with her husband because, her husband, a policeman, had been posted to another city to begin work there and Ernestina was yet to join him at the time of the interview. Apart from Fanny her daughter, and her child with cerebral palsy, she and her husband had other 3 girls in the family. Ernestina usually worked selling slightly used ladies' handbags to make a living. However, at the time of the interview, she had stopped working to care for Alexander and therefore was solely relying on her husband's providence. Fanny, the child's sister, who was 18 years old at the time of the interview, was the eldest sibling in the family. She was in her final year in senior high school and was looking forward to complete soon. She was looking forward to entering the University soon after completing senior high school. Samson, the child's grandfather, who is 50 years old, works as a Christian Pastor. Though Samson does not live in the same house with Alexander's parents, he is almost always in the house to visit and spend time with him every day. With the absence of Alexander's father in the house, Samson, as reported by Ernestina, is like a second father to the child. All three participants in this family subscribed to the Christian faith as their sole religion. These participants were interviewed separately at different locations within their house, to share their experiences during these 6 years 5 months of living with a child with cerebral palsy.

Development of cerebral palsy

Alexander had complications at birth and was later diagnosed with cerebral palsy after frequent visits to the hospital. Alexander had not been enrolled in school as at the time of the study.

4.2.2 Family 2

Child with CP	Barack	6 years 8 months	Male
Florence		Mother	
Arthur		Father	

The second family presented the fewest number of participants (2). The participants were Florence (mother) and Arthur (Father). Arthur and Florence are legally married and live together in a rented apartment in an urban area. Arthur and Florence have 5 children and their youngest, Barack, their only son, who was 6years 8 months old had cerebral palsy. Florence is 34 years old and is a food vendor by occupation. However, at the time of the interview, she had terminated her work to care for Barack in the house and depended on her husband for daily upkeep as well as the other children. Arthur is 42 years old and works in an abattoir. Arthur and his wife were both members of the Islamic faith at the time of the interview. Interviews were held in the house of these participants separately from each other .

Development of cerebral palsy

Barack was born in the 11th month of gestation via normal delivery. After three days of being discharged from the hospital after safe delivery, Arthur, his wife and other members in the family discovered the child's skin and eyes had unusually turned yellowish. Barack was diagnosed with jaundice and an exchange blood transfusion was proposed by the health professionals to which the parents gave their consent. This process was done at the hospital safely with no complications. Delays in Barack's developmental milestones, as he was not able to sit, crawl nor stand, alerted his parents to the fact that there was something wrong and they returned to the hospital, where Barack was diagnosed with cerebral palsy

4.2.3 Family 3

Child with CP	Caleb	8 years	Male
Abraham		Father	
Hannah		Mother	
Mary		Grandmother	

In the 3rd family, three participants, Abraham, Hannah and Mary consented to take part in the study. At the time of the interview, Abraham and Hannah were legally married partners. Abraham and Hannah had 8 children together. Of the 8 children, the

4th child, Caleb, their son, had cerebral palsy. Abraham is 60 years old and works as a traditional cloth weaver and has no formal education. While Abraham's wife and children live in their extended family house, he lives in another house that has close proximity to his wife's family house so he goes there from time to time. Hannah, the mother of the child with cerebral palsy, Caleb, was 40 years old during the time of the interview. She had no formal education and worked as a subsistence farmer but had stopped working to cater for the child with cerebral palsy at the time of the interview. Mary, Caleb's grandmother was 60 years old and did subsistence farming for a living. As at the time of the interview, Mary had stopped active farming because of her asthma and a broken right leg. From the conversation it became evident that Mary had struggled to bear children herself. Mary had therefore sworn to herself that should any of her children give birth, she would support them to care for her grandchildren. Mary, therefore, describes herself as a second mother to all her grandchildren and supports her grown-up children to care for her grandchildren. She even sends money to her grandchildren that do not live in the family house. Mary was once a Christian but had stopped going to church and had resorted to idol worshipping in a fetish house. Mary stays together with Caleb and his mother in a large compound house. she, therefore, helps the mother in the child's daily upkeep.

Development of cerebral palsy

As reported by the parents, the child with CP, Caleb, had a safe delivery at birth with no complications. Hannah attended postnatal visits after delivery, but the cerebral palsy condition was not detected. However, as Caleb was growing up, a delay in his developmental milestones was detected by the parents as a result of them being aware of the developmental milestones of other children. The child was diagnosed with cerebral palsy during these visits. Though the child could walk during the time of the interview, the family still took the child for physiotherapy treatment once a month.

4.2.4 Family 4

Child with CP	Damian	10 years	Male
Duncan		Father	
Lydia		Mother	
Mildred		Sister	

Three participants gave their consent in the 4th family to be part of the study. These family members stayed together in a compound house with Damian, a 10 years old child with cerebral palsy. Lydia and Duncan were a married couple who had 4 children together. Damian, the child with cerebral palsy was the 2nd of these children. Mildred, who was 19 years during data collection, was the senior sibling in this family. Duncan was 45 years and worked as a pastor in his own church in the town in which he and his family live. He and his wife, Lydia, lived in a compound house. The house is an old one with about 20 tenants living in the same house. This house belongs to the family of his wife, thus Duncan lives with his in-laws in the same house. Lydia was 34 years old and had stopped working as at the time of the interview, to cater for Damian. Damian comes next to Mildred, his senior sister. Mildred was a student in her final year in a senior high school and lived with her mum and dad in the same compound house. The family were looking forward to enrol Damian, the child with CP, in a special needs school.

Development of cerebral palsy

According to the family members, Damian developed some complications (skin looked yellowish) during delivery and had to be put in an incubator for about 2 weeks at the hospital. The child’s complication resolved after the incubation treatment and the mother was discharged. However, about 6 months later, Damian’s developmental delay (could not sit, couldn’t move the neck, could not crawl) would make the parents begin visits to the hospital again to find possible explanations for what could be causing this delay. It was during this time that the child was diagnosed with cerebral palsy.

4.2.5 Family 5

Child with CP	Elsie	5 years 8 months	Female
Kennedy		Father	
Harriet		Mother	
Margaret		Grandmother	

Kennedy and his wife, Harriet, lived in a 3 bedroom flat in a rented apartment near the centre of the city where this study was conducted. Elsie, the child with cerebral palsy, was the only child of this couple during data collection. Kennedy is 34 years old and a professional Teacher. Kennedy is one of the junior pastors in his church. Harriet was

29 years old and worked as a graduate teacher. Margaret, a 59 years old woman and the grandmother of Elsie, stays with the parents of the child and also helps to take care of Elsie when they are not around in the house. Sometimes it is Margaret who takes Elsie to the physiotherapy unit for strengthening exercises.

Development of cerebral palsy

Harriet encountered a very difficult labour period and she spent about 6 hours at the delivery room before Elsie was finally delivered. After delivery, the health professionals noticed the child was asphyxiating and had to quickly put her on a nasal cannula to supply some oxygen to her lungs. Elsie also had to be put in an incubator after a couple of days before being discharged. However, as she was growing up, a delay in her developmental milestone (could not sit, crawl nor stand, head and neck movements became difficult) brought the perception that there was something still wrong with the child. They started going to the hospital again and Elsie was diagnosed with cerebral palsy during this time.

4.2.6 Family 6

Child with CP	Felix	7 years 5 months	Male
Nelson		Father	
Lizzy		Mother	
Lisa		Sister	

In the 6th family, three participants, the father, the mother and a sister of the child with cerebral palsy, Felix, consented to be interviewed for data. There were 8 children in this family and Felix was the 5th child. All three participants lived in the same compound house with other tenants who were not part of the family. Nelson, Felix’s father, was 40 years old and worked as a trader who sold second-hand clothing to support his family. Lizzy, Felix’s mother, who was 36 years old had fallen out of work, after Felix was diagnosed with cerebral palsy, in order to care for him. Hence, the family was dependent on the father’s income for survival. Lisa, the oldest of the children, who was 18 years old, was a student in the senior high school and had to be a day student instead of living in the boarding house, so she could help take care of Felix.

Development of cerebral palsy

The family reported normality of the child's delivery during birth and no complications happened. However, a little over a year later, when Felix was expected to be crawling and walking, he couldn't do so. Nelson and his family suspected that there could be something wrong with Felix. They began visits to the hospital to find out what could be wrong with the child's development and the child was diagnosed with cerebral palsy during this time.

4.2.7 Family 7

Child with CP	Geoffrey	8 years	Male
Norman		Father	
Nancy		Mother	
Rudolf		Brother	

In the 7th family, three participants also presented themselves to be interviewed and this comprised the father, the mother and a brother of Geoffrey, the child with cerebral palsy. Norman, the father of Geoffrey and his wife, Nancy, lived together in the same house with Rudolf, their firstborn child who was 19 years old during the time of the study. Norman was 47 years old and worked as a butcher. Norman's work was the only source of livelihood for the family as his wife, Nancy, who was 40 years old, had stopped working to take care of Geoffrey after he was diagnosed with cerebral palsy and had become highly dependent. This couple had 9 children in the family including the child with cerebral palsy. Rudolf, the senior sibling, was a student during the time of the interview. To support his parents, Rudolf sometimes helps to look after his brother, Geoffrey, when the parents are not around.

Development of cerebral palsy

Norman's wife, Nancy, gave birth to two twin boys. Their delivery had no complications so they were discharged to the house early. Norman and his wife however, discovered later that the younger of the twins, Geoffrey, had turned yellowish. There was a delay in sending Geoffrey to the hospital to find out what could be wrong. Instead, they visited a herbalist who gave the child some treatment and encouraged them to lay him in the morning sun every day. However, after some days, the yellowish colouring had still not cleared so they decided to send the child to the hospital. The parents reported that the staff helped treat Geoffrey and the yellowish

colouring on his skin disappeared. However, a little over a year later, they saw a delay in Geoffrey's development as he could not sit nor crawl and had to report the condition to the health professionals again. Geoffrey was later diagnosed with cerebral palsy.

4.2.8 Family 8

Child with CP	Heather	5 years 3 months	Female
Betty	Mother		
Emelia	Grandmother		
Maud	Aunt		

In the 8th family, a mother (Betty), a Grandmother (Emelia) and an Aunt (Maud) agreed to take part in the study. Betty was a 37 years old woman who had given birth to two children. The youngest, Heather, who is 5 years 3 months old, suffers from severe cerebral palsy. Betty had a man in her life (the father of the child) but had not officially gotten married to him. The man rather promised Betty that he was going to marry her after she has given birth. On giving birth, Heather developed the cerebral palsy condition so that marriage promise had still not taken place because of both parents spending more on finding a remedy for the child's condition. Betty made me understand that the man has not given up on her and still holds on to his promise of marrying her soon. Betty was a bar attendant but after giving birth to Heather, she was not very regular at work and was therefore dismissed from her job. Therefore, Betty was not working at the time of the interview and depended on the father of the child for survival. Emelia, 65 years old, is Heather's grandmother and lived in the same house with this child and her mother, Betty, who is also her own blood daughter. She was working as a trader of second-hand clothing during the time of the interview. Maud, an Aunt to Heather, the child with cerebral palsy, who was 38 years of age, lived in a different house with her husband but she went to the family house frequently to give a helping hand to Betty, her junior sister, to take care of the child. It was routine for Maud to go and visit Betty and the child at least once in a day. Maud was married with three children.

Development of cerebral palsy

Betty had a safe delivery during birth. However, a few days after being discharged to the house, she spotted the skin of Heather had turned yellowish and therefore sent the child back to the hospital. Heather became well again, however, in the later

months, the parents suspected her mobility was impaired as she was not able to sit, turn her head, crawl, etc. This made the child's parents suspect that there could be something wrong with her. Medical examinations done at the hospital would later reveal that Heather had developed cerebral palsy.

4.2.9 Family 9

Child with CP	Ivan	6 years	Male
Deborah		Mother	
Natasha		Grandmother	
Peter		Grandfather	
Portia		Aunt	

Family 9 presented the highest number of participants for the interview in this study. It comprised the Mother, Grandmother, Grandfather and the Aunt of Ivan, the child with cerebral palsy who was 6 years old. Debra, the mother of Ivan, was 33 years old and this was her 2nd child with her husband. She worked as a trader but had ceased working to take care of Ivan, the child with cerebral palsy. Natasha, the grandmother of Ivan, was a 62 years old woman and lived with her husband, her son (father of the child with CP) and her daughter-in-law in the same house. Natasha sold groceries to make a living. Peter, a 73 years old man and the grandfather of Ivan, was the husband of Natasha and operated the same grocery store located in front of the house the family abode in. Portia was the Aunt of Ivan, a 40 years old woman who operated in selling electrical wares on retail in a shop not far from the family house. All these family members helped the parents to take care of the child with cerebral palsy.

Development of cerebral palsy

According to the mother and other family members, Ivan was delivered pre-term (7months) and the mother was therefore admitted at the hospital for some period of time so health professionals could monitor the child's condition. About 7 months after being discharged however, family members noticed how Ivan was not improving in mobility as his sitting and bodily movements were delaying. The mother was therefore prompted to take the child to the hospital. Examinations were done at this period by healthcare professionals and the results showed that the child had developed cerebral palsy.

4.2.10 Family 10

Child with CP	Jayden	6 years	Male
Nora		Mother	
Rita		Sister	
Leah		Sister	

In the last family, a mother and her two old children (sisters of the child with cerebral palsy) consented to participate in the study. Nora, the mother of Jayden, the child with cerebral palsy, was 39 years old and worked as a food vendor but like the other mothers in the study, she had dropped out of work to take care of Jayden. Rita, the oldest sister of Jayden, was 26 years old, was married with two kids and lived in a separate house. She, however, visits her mother's house frequently to support her mum in taking care of Jayden especially when her mum had to travel. Rita worked as a caterer. Leah, the last participant in this family, was 23 years old and had just graduated with a diploma in nursing and was looking forward to being employed. This family was dominated by women and the child with cerebral palsy was the second of two boys and the last child in the family.

Development of cerebral palsy

Nora, Jayden's mother, experienced a birth delay during labour. It was reported that her delivery took a considerable long time before the baby was born. Health professionals had to do an exchange blood transfusion for the child as well before the mother was discharged. About some months later, when the family members noticed that Jayden's mobility was being delayed, they suspected something could be wrong and therefore sent the child to the hospital for medical help. The child was diagnosed with cerebral palsy after biomedical examinations by health professionals.

4.3 Conclusion

This chapter has attempted to demonstrate participant contexts through the presentation of participant demographics and factors that led to the development of cerebral palsy in the children they stayed with. The subsequent three chapters will present the study results.

CHAPTER FIVE: THE RESTITUTION NARRATIVE

5.1 Introduction to study findings

The narrative typologies of Frank, i.e. Restitution, Chaos and Quest, have tended to focus on the experiences of the embodied being, that is, the sick person or the person living with chronic illness and have not paid attention to the persons in the lives of the sick person. The results of this study will demonstrate that members living with children with cerebral palsy tell the narratives of restitution, chaos and quest constructions of human experience of illness. Moreover, as Frank's narratives have focused on the illness experiences of western culture, this study portrays that the illness experience narrative in western culture may not be different in structure from underdeveloped cultures but may differ in content. This chapter and the subsequent two chapters will present findings from the narrative thematic analysis of the interviews conducted with family members of children with cerebral palsy. Thematic analysis of the interviews was data-driven (inductive codes rather than deductive codes were used), and interpretation and understanding of the findings were done deductively utilising and extending the narratives of Frank.

5.2 Summary of how the narratives occurred in the study findings

The narratives captured from data were deeply grounded in their experiences as a result of living with children having cerebral palsy. The findings from the data analysis of this study will demonstrate that regardless of the heterogeneity between participant groups interviewed (whether mothers, fathers, siblings or extended family) a common story was evident from the data and this story was constructed around the restitution, chaos and quest narratives. These portrayed a shifting dominance and movement and it was observed that participants commenced their stories with the restitution narrative at the point they became aware of the children's condition. All participants appeared to expect restitution to be fulfilled in the lives of the children. However, this narrative changed to chaos when they found that the restitution they expected was not forthcoming (i.e. both biomedical and alternative medicine failed to provide a cure and that the condition had a long-term nature). The chaos narrative was influenced by the impact of having to live with a child with cerebral palsy and the cultural or societal opinions that family members encountered, making participants feel they have lost control over the children's condition. The quest narrative emerged when participants

constructed meanings to what cerebral palsy meant for them and the quest narrative was mostly underpinned by religious beliefs. However, it must be emphasized that the restitution narrative never went away and was always at the background whenever a different narrative took the foreground position: participants lived in hope of the children eventually getting well or finding a cure, making the restitution narrative the dominant narrative. Table 10 demonstrates Frank's Narrative types using examples from the data collected from study participants

Table 10: Demonstration of Frank's narrative types with examples from data

Narrative Types	Example From Participant Data
<p>1. Restitution This narrative demonstrates that to every illness, there is a remedy. The narrative portrays that illness is transitory and beliefs in the restoration of health</p>	<p><i>"We have been attending the physiotherapy treatment till this day. We attended twice a week when we started but now it is once a month...and if there is any medicine that would cure him completely and they help me with that, I would be very grateful"...Abraham (Father)</i></p>
<p>2. Chaos The chaos narrative portrays a loss of control as its major plotline. It imagines life never getting better as a result of illness</p>	<p><i>"It wasn't easy for me to take it when they told me my child has cerebral palsy and explained the nature of the disease to me. The news came as a shock and I didn't know what to do about it. When I was told my child had cerebral palsy, I did not know when I descended the staircase to the ground floor. Before I realised, I had gone out of the hospital and was outside. You know there is a motorway in front of the hospital which one must cross if she wants to get to the other side. I was crossing the road without looking out for any approaching vehicle. When I came to my senses, a middle-aged woman had grabbed me and was pulling me to the pavement. I was nearly knocked down by a car. The horns of the car had honked thrice on me but I didn't hear of it till the woman who sells some porridge outside the hospital, grabbed me and told me what nearly happened to me. I looked back at the driver who had then stopped on the road and was looking at me in amazement and apologised"Nancy (mother)</i></p>
<p>3. Quest The quest narrative meets suffering head on and attempts to use it. It romanticises the illness condition in an idealistic or unrealistic fashion, making it appear better or seem better than it really is. Individuals also make meaning of the illness in the quest narrative.</p>	<p><i>"I think that God wanted the condition to be on the child, the reason the child was not cured. If it wasn't God's will that this condition should happen to the child, I believe it wouldn't have happened. I have given birth to five children but did not see any of such conditions in my children. So, I believe that it is the will of God that has happened" ...Natasha (Grandmother)</i></p>

5.3 The restitution narrative

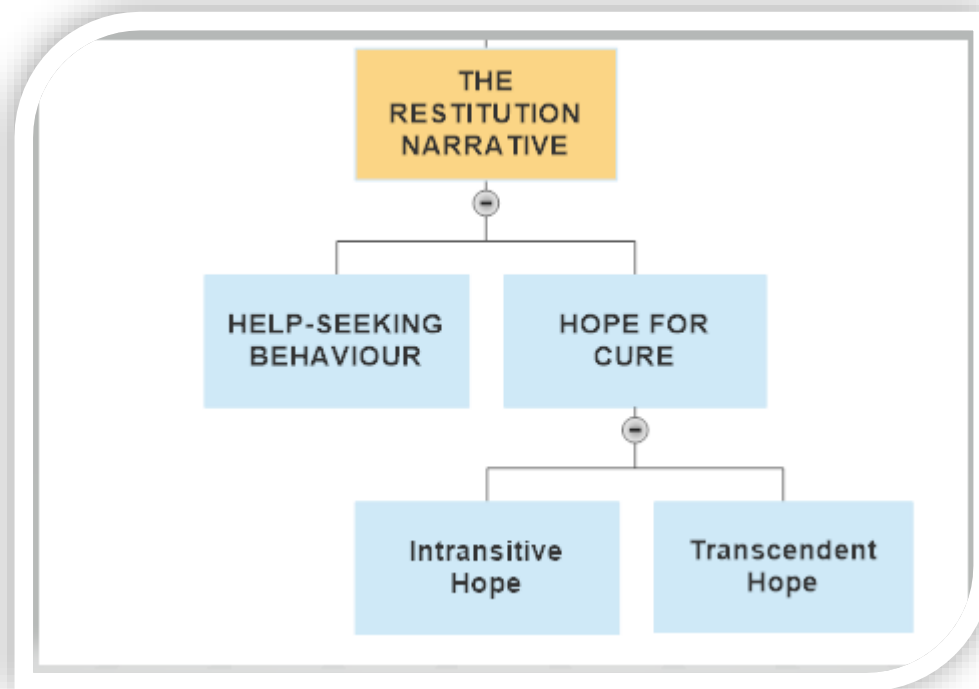
5.3.1 Introduction

From the stories participants told, the restitution narrative appeared to be the one most desired and returned to. These narratives were characterised by family members suspecting something was wrong with the children, seeking treatment for the children and the expectation that the children would be restored to health, which is consistent with the restitution narrative that to every illness there is a cure (Frank, 2013, Diver et al., 2013b). The restitution narrative was enacted by all groups of participants but it was dominated by parents and in particular, participants' journey of seeking possible remedies for the children's condition.

Participants told both retrospective and prospective restitution stories. The retrospective restitution narrative was influenced by how they sought to resolve the children's condition in the past (help-seeking behaviour) and within the prospective restitution stories, participants expressed the desire, hope or a wish, for a time when the children would be returned to "normal state of health again", this meant that the desire for restitution never went away. It must, however, be emphasized that the presence of the restitution story and its reappearance within their stories, did not have a linear occurrence and neither did it occur at consistent time frames due to the fact that other narratives intruded the restitution narrative.

The restitution narrative was underpinned by two themes: *Help-seeking Behaviour* and *Hope for cure*. The *Hope for cure* theme is underpinned by two sub-themes: *Intransitive hope for cure* and *Transcendent hope for cure*. These are represented diagrammatically in figure 9.

Fig. 9: A diagram showing the restitution narrative, themes and sub-themes



The next sections will present an exposition of the themes and sub-themes that underpinned the restitution narrative.

5.3.2 Help-seeking behaviour and the restitution narrative

Help-seeking behaviour, a theme in the restitution narrative, characterized the major part of this narrative. This is because family members explored different means of finding restitution for the children, when they began to suspect there might be something wrong with the children and when the children were diagnosed with cerebral palsy. It demonstrates when study subjects perceived there was something wrong with the children, when the children were diagnosed with cerebral palsy and how they expected restitution to happen for these children. Physicians, nurses, therapists and other clinicians were also active players in the stories participants told within the restitution narrative.

The journey of seeking help for the children began at the stage where it was noticed that “something was wrong”; this was mostly in relation to the delay in behaviours or physical skills as they grew and developed. Such physical skills included a delay in rolling over, sitting up, crawling, head control, etc. This was typified by statements

made by Margaret, the grandmother of Elsie, who was 5years 8months old child with cerebral palsy, and Maud, the Aunt of Heather, a 5years 3 months old child with cerebral palsy. Margaret reported the family noticed a delay in her grandchild's development and therefore suspected or perceived that something could be wrong with the child.

"We (family members) realised it when she was above 4 months. I know that from 2 months a child should start to sit and she should have mastered sitting when she is above 4 months and can, therefore, sit on her own but her situation was different. We tried sitting her, but she found it difficult doing it. I saw her mother was always struggling to draw her breastmilk with the syringe so after some time I told her to stop it and try putting her nipples straight into her mouth. She couldn't hold her mum's breast with her mouth and suck so what we did was I would hold her head and her mum would put her breast into her mouth"..... Margaret (grandmother).

Maud had also noticed her niece was struggling with turning and head control.

"When you go to her in her room, you know a child is expected to turn her head to look at you when she hears any noise but this child would hear the noise in the room but wouldn't be able to turn to look at the direction the noise is coming from. We also noticed her eyes were also not able to see properly. It continued for six months and this child couldn't sit or turn to look at anyone".... Maud (Aunt)

The perception that something could be wrong with the children at the pre-diagnosis stage, was demonstrated by participants in three different constructs. In some families, parents were aware of the accepted developmental milestones with their children and, therefore, suspected "something was wrong" when these developmental milestones were delayed. It appeared that parents who were aware of the delayed milestones pertaining to the children's development were mostly those who had other children, and were well acquainted with child development. This is highlighted by Abraham, who had 8 other children with his wife, Hannah.

"The child looked very strong and healthy when he was born. We didn't see anything that was wrong with the child. My wife also went for postnatal visits as was prescribed by the nurses. The only time we discovered something

was wrong with him was when it was time for him to walk but he couldn't. This was when we realised something was wrong with the child. When his sitting time was due, he could sit alright so we didn't see anything wrong until the time when his walking was overdue, but he couldn't walk" Abraham (father)

However, within other families parents failed to notice the delay in their children's development and had to be prompted either by other members of the extended family or by friends that something was not well with their children and as a result had to seek help.

"My sister-in-law sent the child to her hometown in the north. When she returned from her hometown, the child was fine until later when I discovered the child had changed. He wasn't looking normal. I did not notice the child had any problem until he reached the stage where he was supposed to sit but couldn't, that was when I noticed the child was sick or not well. This continued for many nights, so we became concerned about it. So, we told the mother that the child crying every night is not a normal thing" Portia (Aunt)

"At first I didn't realise it until people who used to visit me and the child at home started drawing my attention. Most of the people complained that the child's neck wasn't as stable as expected on a normal child but I somehow ignored until I went to church for thanksgiving that one elderly woman who took the child from me complained seriously that there was something wrong with the child's neck and that at his age he looked very weak and frail".....Ernestina (mother)

Irrespective of the various ways in which family members became aware that something could be wrong with the children, it appeared there was uniformity across participant views that they felt a need to seek help. However, it appeared restitution narratives were commonly expressed by participants at the pre-diagnosis stage, as they felt that what was wrong with the children may not have a long-term nature and could be resolved like any other illness when sent to the hospital. Hence, it appeared participants felt that the children's condition could not be serious and they had hoped

that what was wrong with the children, like any other illness, could be resolved through healthcare intervention.

“We took it as a normal thing like any other normal illness that would be cured. We never thought it would generate into this condition”.....Norman (father)

“We never suspected anything bad and thought it was like any other illness that could be cured. I never expected it could turn out like this” ...Maud (Aunt)

Decisions were therefore made in the family to seek appropriate help or treatment and this action evidenced the “to-every-illness-there-is-a-remedy” plotline of the restitution narrative. In families where the parents noticed that something was wrong with their child, decisions to seek remedy originated with the parents themselves; in other families where parents had to be prompted by other members from the extended family that something could be wrong with the child, decisions to seek remedy was suggested or encouraged by the extended family members. This finding depicts that both nuclear and extended family members were involved in seeking restitution for the children. However, in the initial stages of seeking help, siblings and extended family members participated passively by hoping the children’s condition could be resolved when taken to the hospital whereas parents participated actively at the initial stages by taking the children to the hospital themselves.

“Errrm at the beginning, when the condition was starting, the mother was going to-and-from the hospital every day”.....Portia (Aunt)

“My wife suggested to me that we take the child to the hospital, which we did”... Duncan (Father)

An example, which demonstrated that parents, especially mothers, were at the frontline of seeking help for the child at the pre-diagnosis stage is given by Rudolf, a 19-year-old sibling to Geoffrey, an 8 years old child with cerebral palsy. Rudolf described how it was suspected that something could be wrong with Geoffrey after the family had observed some developmental delays as the child could not sit nor crawl in a little over a year after he was born. Rudolf thought his mother instigated a visit to the hospital and subsequent visits, to find out what was wrong.

“So, mum started frequenting the hospital several times. My sister was admitted and discharged on several occasions during this period. So finally, my mum sent her to the hospital where the twins were born”.... Rudolf (brother)

Therefore, the delay in the developmental milestone of the child, perceived by participants as “something was wrong”, led most participants to seek for an explanation or solution within the biomedical model of healthcare, an action which further enacted the restitution narrative and for all the participants help was sought within a short period of time after recognising the delay in the developmental processes of the children. The place of first presentation of the child for possible explanation and treatment for most participants was at the hospital.

The majority of participants’ restitution narrative at the pre-diagnosis period appeared intimately related to a biomedical approach as they endeavoured to seek expansive explanations to what could be possibly wrong with the children. However, two of the participants, Nancy and her husband Norman, presented a different opinion about seeking biomedical help at the time of suspecting “something was wrong” with their child. This was because Nancy had suspected that her child was not well at birth but had been assured by a healthcare professional that the child was in good health and would be fine.

“The junior one which now has cerebral palsy was behaving so unusual when I saw him [a short time after delivery]. I have nine children and didn’t see such behaviour in them during delivery except for this one. His behaviour was so unusual, and I did not know what was happening to him. I complained to one of the nurses that the senior of the twins was very quiet but the junior one kept crying. The nurse came to my bedside, took the child and looked at him for some time and told me “he is fine, nothing will happen to him”. He was crying profusely and was stretching his body repeatedly but the nurse I complained to, told me nothing would happen to him and that I should breastfeed him continuously and when he’s had enough he would stop crying. The nurse just said that and went away, so I did exactly what she told me. I was later discharged from the hospital and came home with the babies”.... Nancy (mother)

However, from Nancy's report, they perceived the words of the healthcare professionals were not true as the couples noticed developmental delays in the child about 4 to 5 months after being discharged to the house. However, when Nancy and her husband noticed some developmental delays and suspected that something was indeed wrong with their child, they refused to take the child back to where he was delivered but rather sought the help of a herbalist. It was also evident from Nancy's narration that the members of their household also reinforced that the child's condition did not require any biomedical help but rather an alternative one (herbalism).

Nancy:

Yea, so, I went to see the herbalist and he gave me some herbs to be given to the child

Interviewer:

Why didn't you send him back to [hospital name] after realising he was not in good condition?

Nancy:

One of the nurses at [hospital name]], after looking at the child [at birth], told me there was nothing wrong with him and that he would be fine that was the reason I didn't send the child back. I also believed in what the home folks told me, that it wasn't any bad condition and if I apply the herbs the child would be fine.

"He was taken to an herbalist because we thought it wasn't a condition to be treated at the hospital. It was only when the herbalist failed to treat him that we sent him to the hospital".... Norman (father)"

Norman and Nancy's first point of call to seek explanation and solution was therefore within the complementary or alternative healthcare model when they suspected something was indeed wrong with their child. Thus, at birth, they sought advice and were reassured nothing was wrong, however, later on when they had further concerns, they sought an opinion outside the biomedical model.

Even though their actions in seeking help somewhat contradicted that of the other participants, they were still consistent with the restitution narrative of finding a solution to an illness condition. However, Norman and Nancy would seek conventional help later, as alternative treatment failed to give proper diagnosis or possible explanation to the child's condition. This is typified by Nancy's statement below:

"I continued giving the green solution from the boiled herbs to the child but realised his condition was still the same so I then decided to take him to the hospital when I went for my review. It was at the hospital that they told me his condition had already worsened adding that I should have brought him to the hospital on time.....Nancy (mother)

He was taken to a herbalist because we thought it wasn't a condition to be treated at the hospital. It was only when the herbalist failed to treat him that we sent him to the hospital".... Norman (father)

Health professionals dominated this part of the narrative as they conducted a variety of tests to determine the reason for the presenting complaints from participants who had expectations of getting explanations to what could be possibly wrong with their children

"Yea so we sent her to [hospital name], and they did all kinds of examinations on her including x-rays on her legs and eye check" ...Maud (Aunt)

"They referred me to the x-ray department to have a picture of her neck. They told me they would send the x-ray results to me on my phone when the results were in" Betty (mother)

Participants gained insight into what could be possibly wrong with the child. They received a diagnostic label and biomedical explanations as to the cause of cerebral palsy as noted through the extracts below:

"They told us this condition normally happens to children during their childhood days. They mentioned many causes of this condition but the only ones I remember are that they said when you give birth to a child and his weight is very low, it can result in this condition, yes. Aha, I also remember they said the disease has got some kinds, we have a mild one and a severe

one. I was told he had the severe type and added that if we do whatever they told us to do for the child, he would walk” Mary (grandmother)

“I was told that when the mother is in labour and the birth of the child delays, it can result in this condition. That’s what I know about the condition.... Leah (sister)”

“The doctors said it would take a long time before her neck would become stable. They also said her sitting, crawling, walking and talking would delay and these are also obvious on the child” ...Kennedy (father)

Health professionals further appeared to be placing greater emphasis on restitution as they counselled participants on the available rehabilitation support for the children and suggested physiotherapy treatment for the children to commence as soon as possible.

“One of the doctors asked us to take her to the Physiotherapy unit for exercises because her sitting was delaying. She was growing but she couldn’t sit” Margaret (grandmother)

The retrospective restitution narrative moved chronologically from the point of diagnosis but within the diagnosis point of the experiential process, the chaos narrative intruded (see chapter 6 section 6.2.1). This, therefore, meant that restitution was an underpinning and consistent narrative to the point of diagnosis, but the chaos narrative occurred concurrently with restitution. The feelings expressed by participants at the point of diagnosis had the chaos narrative plotline (section 6.2.1). However, participants returned from chaos to the restitution narrative again as the children were scheduled to attend routine conventional treatments (Physiotherapy). Mostly this was twice a week at the initial stages, decreased to once a week and limited to once a month based on the expert opinions of professionals. All parents adhered to this arrangement. Furthermore, at this point, siblings and extended family members began to enact restitution actively as they appeared to join the parents actively in seeking treatment for the children. Their actions supported the restitution narrative as they thought the children would “get well soon” or become “independent” though health professionals had not assured them of this.

“And when we got to the physio unit, they told us to bring the child to the hospital every 3 days for treatment exercises. We followed their treatment

regimen because we wanted the child to get well soon. We continued going to the hospital for the exercises and we have been attending the physio till now. At first, it was twice a week but now that he is quite grown and in school, it is just once a month”....Mary (grandmother)

“We tried to help with her exercises prescribed by the hospital at home so she would become independent”....Rudolf (sibling)

All children were attending physiotherapy treatment at the time of the study. It appeared that participants enacted the restitution narrative by expecting a certain desired outcome (the children getting well) some few years on from the rehabilitation exercises their children attended. However, their expectations were largely unmet. From the view of participants, they had expected biomedical treatment to have brought some improvements in the developmental milestones of the child or to have provided a remedy for the child’s situation, but their expectations were not met. Speaking about unmet expectations in biomedical treatment, two participants highlighted.

“We continued with this for about two years, but she was still not improving. She was not able to sit nor walk and her neck was very weak and couldn’t stand” Maud (Aunt)

“We have been going for physiotherapy till now but still we have not seen any improvement. We wonder if this will help the child. There have been many times that we don’t send him for treatment because we don’t see an improvement. Sometimes we feel like stopping this physiotherapy treatment thing altogether” ...Natasha (Grandmother)

From Natasha’s narration, failure of biomedical treatment to provide the outcome they had expected had even led to inconsistencies in their attendance to physiotherapy treatment for the child and this failure threatened the continuity of the conventional rehabilitation she was attending.

Failure of biomedical treatment to meet the expectations of participants was significant in their narrative as it led participants to consider alternative means of treatment to augment the chances of restitution happening for the children with cerebral palsy. Participants still tried to find a way of fulfilling the “today I am sick, tomorrow I will get better” restitution plotline in the lives of the children. They endeavoured to fulfil this

restitution plotline by seeking alternative help for the children with the hope that where biomedical help had failed to offer an expected solution, complementary medicine could help with the desired outcome, an action which further deepened their desire for restitution to be achieved in the lives of the children. Participants often, therefore, complemented biomedical treatment with alternative treatment (mostly herbalism)

Interviewer:

And you had been doing this [alternative treatment] in addition to the physiotherapy exercises?

Florence:

Yes, I did both together. For the physiotherapy exercises, I have never refused an appointment since I started. I make sure I honour all appointments with the therapists. And for the herbs, some herbalists would instruct me to apply them as topical creams on the hands, legs, and neck of the child. Some would also instruct me to make the child take it orally. I did them together

This finding is also typified by Ernestina's statement, the mother of Alexander, a 6 years 5 months old child with cerebral palsy. Ernestina and her husband had 3 other children and Alexander was the only male child among the children. They had hoped for a boy and it was an immense joy when they finally had Alexander. Unfortunately, their happiness was short-lived as Alexander was diagnosed with cerebral palsy and they got to know more about its long-term nature. After their child was diagnosed with cerebral palsy, they heeded professional advice and started physiotherapy management at the hospital for the child. Having consistently attended physiotherapy treatment for some years, they had expected much more improvement in Alexander's condition and some independence but their expectations were largely unmet. Still hoping for a cure, it appeared it was discussed within the family, and the extended family encouraged and "advised" the parents to combine an alternative source of treatment with the ongoing biomedical one. They started using alternative herbal treatment, hoping that with the combination of these two treatment approaches, restitution could be realised for the child. Asked about her engagement of both biomedical and complementary treatment, Ernestina stated:

“My mother, the child’s grandmother, therefore advised me [when biomedical treatment was not meeting expectation] to look for some local herbs to treat the child. I remember when I was pregnant with this child, I used to go for some herbs from one native doctor at Bibiani in the western region, so I went back to seek his help at this time”.....Ernestina (mother)

It appeared that within the families, all the different participant groups were involved in actively seeking for an alternative help for the children as they seemed to report encounters with traditional healers, application of traditional medicines and also expressed some beliefs in traditional medicine. This is demonstrated by the quotes below.

“I remember a woman met me at the hospital one time and told me that she had the same child like mine but somebody showed her some herbs which were very potent. She applied the herbs topically on the child and now her child started walking. I asked for the herbs and she showed me, so I also applied the herbs on my child for six months”Abraham (father)

“Mmm, yes, I remember we took her to one woman herbalist who is also a pastor. That woman through her herbs was able to make the child sit on her own. I guess if we had gone to the woman earlier, the child would be walking by now. So it is that woman that made the child sit on her own. Yea, and it is a testimony. The woman made the child sit down without being assisted”...Emelia (Grandmother)

“At first, the child couldn’t stand on his feet when you try to assist but since the man started applying the herbs on him, he can stand with assistance. His hands were also severely bent and couldn’t even stretch but now his hands have started becoming flexible gradually. So, I believe the herbs from the native doctors were effective”....Samson (Grandfather)

“The child had tilted to one side before we started the application of the herbs and after applying the herbs for some time, we could see that his body was gradually assuming a normal shape”...Leah (sibling)

However, there was a lack of transparency with healthcare professionals on the part of participants during encounters, on the alternative help they were receiving.

Participants appeared to seek and receive alternative help without disclosure to the healthcare professionals or therapists.

“Most of the time, we the parents who have children with this condition go behind the health professionals to seek help from other people. You often meet people who would tell you, “I have encountered someone who had a child with this same condition and directed him to a man who helped him. I think if you go to see that man, he will be able to help your child as well”. So, we go behind health professionals to see herbalists for help very often”.... Arthur (Father)

For the study participants, the threshold to step beyond the boundaries of biomedical help was defined by their perceptions that the children were not improving in their developmental milestones. They appeared desperate for restitution to be achieved in the lives of the children by any means possible, making them vulnerable to suggestions from people who knew where alternative help could be found. This is typified by Arthur, a Muslim father, who believes that having a boy in the family is a blessing; a boy is supposed to succeed his father and assume his father's role in the family. The diagnosis of cerebral palsy, however, threatened his future intentions for his child as he stated in his interview:

“When I heard the child's brain was affected and that he might mature into adulthood with his condition, I became extremely worried. I thought about the fact that my dream for him may not come true because of his affected brain. This was what went through my mind and made me worried”.

After accessing physiotherapy for a number of years in the hope of restoration of his child's health, he could see no improvement in his child's condition and felt that the threat to his intentions for his child could become a reality. He became concerned and desperate to find cure wherever possible and this made him step beyond the boundaries of biomedical treatment, to access an alternative treatment for his child.

*“You become vulnerable to the directions that people would give you and you follow them to anywhere you would get [alternative] cure for your child. So, I went to see herbalists that people suggested to me for help very often.”
...Arthur (father)*

With both biomedical and alternative treatment being used, some participants had expected improvement with their children's condition, however, it appeared there was no observable improvement. Many of those participants expressed their frustrations and disappointments with alternative treatment. For instance, Peter, a grandfather to a 6years old child with cerebral palsy had thought that the alternative herbal treatment could have restored his grandchild to health. It appeared Peter became frustrated as he felt that those herbalists had taken advantage of the child's situation to make money from the family but couldn't restore the child to health.

"We gave him to some herbalist to take care of the child and cure his condition but whatever the herbalist tried brought no results. Many herbalists have taken huge amounts of money from us and gave us assurances that the child would be cured but they couldn't restore the child to health. We took the child to about three herbalists but none of them was able to cure him as they promised".... Peter (Grandfather)

However, some participants acknowledged some appreciable improvements in the children's condition and in their hope of still achieving restitution for their children, it appeared that these participants felt combining these two approaches of treatment could truly bring the desired outcome they expected in their children. Embedded in the statement made by Arthur, was this notion

"Truly, the physiotherapy treatment has been of help to the child. The training [rehab exercise] has also contributed to the child's ability to stand with assistance. The herbs have also made him stronger than he was before. The herbs have supported the child to be able to turn his neck sideways. It has made the child stronger. So, I would say the professionals can consider the herbs in addition to the physiotherapy exercises. The herbs can be used to support the children whiles they continue doing the physiotherapy exercises. I would implore the professionals at the hospitals to mount some research into some of these herbs and find out which ones are good for treatment and which ones are not good. If this is done, it would go a long way to help us all".... Arthur

From the Above statement, Arthur acknowledged the role of both biomedical and alternative approaches to his child's condition. It appeared he thought that if a cure

was to happen, both biomedical and alternative approaches must be used complementarily and not in competition with each other. He further suggested an empirical investigation into some of the existing alternative treatment approaches to ratify their authenticity so they could complement biomedical treatment in the management of cerebral palsy. It appeared that he was convinced if health professionals could ratify the authenticity of alternative treatments (herbalism) and accept its use to complement biomedical treatment, curing cerebral palsy would be possible.

It also appeared that Arthur's belief in combining both alternative and biomedical treatment to bring about the desired expectation resonated through other families. Asked if alternative treatment could support biomedical treatment to achieve the expected cure, Samson, the grandfather of a child (6 years 5 months old), expressed the view below:

"I am convinced that the native doctors have their part to play and the trained doctors in the various hospitals also have their part. For instance, the native doctors don't operate with any sophisticated machines, but the hospitals have machines they operate with. You can be passed through various screening and scanning machines at the hospital for them to know what exactly is happening in your body, but the native doctors do not do these scanning and screenings. So, I believe taking herbs and going to the hospital walks hand in hand and this means that whiles visiting the native doctors for herbs or leaves you must also visit the hospital as well. I always advise the child's mother to visit the hospital as well whiles using the herbs for the child. So aside applying the herbs, she also takes the child to the hospital every Tuesday for exercises" ...Samson (grandfather)

From their narratives, it was evident that whilst some participants had observed an appreciable improvement in the children's condition, after combining both alternative and biomedical approaches, this did not have the curative outcome they had hoped for. It appeared participants came to realise the long-term nature of cerebral palsy and they felt they could not do anything more related to the treatment of the children's condition, whether biomedical or alternative treatment. This was when there was another movement from restitution to chaos with restitution being relegated again to

the background (see chapter six section 6.2.1). Though the chaos narrative became the dominant one when in the perception of the participants both biomedical and alternative medicine had failed to provide cure, the restitution narrative was not completely abandoned. Participants were resigned to restitution happening for the children on one level but on another level, they still never let go of the hope for a cure.

5.3.3 Hope for cure and the restitution narrative

The analysis of data revealed participants hope for restitution that was expressed in prospect, i.e. a restitution they were looking forward to or expected to happen in the future. However, it was interesting to discover that this prospective hope or desire for restitution to occur, was not based on either biomedical intervention or alternative (traditional treatment). It has been demonstrated in the previous sections that chaos became the dominant narrative when the endeavours of participants for restitution to occur had provided no results. However, at the background of the chaos narrative, there remained a longing for cure with restitution resurfacing again but this time expressed intransitively and transcendently.

- 1) Hope for a cure that has “no specified object or direction”, Intransitive hope (Frank, 2013, p.232)
- 2) Hope for cure based on God’s intervention influenced by religious beliefs (transcendent hope)

The hope for cure appears to reinforce passive restitution, as participants seem to shift from actively engaging restitution to becoming passive, hoping for restitution to occur intransitively and transcendently

5.3.3.1 Intransitive hope for cure

The Intransitive hope for cure was based on restoring their hopes for restitution via the notion that cure may happen eventually based on no physical intervention as the children continue to grow. In constructing this hope of restitution, they left the future opened for the possibility of the children getting well.

This was primarily the narrative of mothers and siblings but not fathers and extended family members. It appeared it was strongest at instances where some siblings and mothers reported some mobility efforts made by the children with CP and this made

them maintain that their children would eventually get well with time as reported by, Fanny, a sister to a child with cerebral palsy

“He is very active. Whenever I lay him down on a mat to exercise him, he makes some appreciable efforts to get up on his own. This gives me the hope that he will soon walk and be independent. The child will walk no matter his circumstances” Fanny (sister)

For some study respondents (mothers), it appeared this intransitive hope for cure continued to be maintained despite the realisation that this hope was unlikely to be fulfilled but the mobility efforts made by their children would make them continually cling to this hope

“Though I have been told [by health professionals] my child would not walk again but I still believe in my heart that he will walk one day. Sometimes in the night, you would see him lifting his arms and feet while stretching himself at the same time on his mat. I would be stealing glances at him at such times and it would make me feel that the child will rise one day and walk. I know he is going to walk one day”Nancy (mother)

The above statement highlights a capacity to maintain hope of recovery even with the increasing realisation that this hope would not occur, and many respondents subscribed to such hopes expressed by Nancy in a similar way.

From the participant narrative, it also appeared that this hope for cure was co-constructed through others' opinions which seemed to reinforce their hope that their children would eventually get well. This is embedded in the statement of Florence who in her daily life as a mother comes into contact with people who would get surprised at seeing a child of 6years 8months old, still dependent on his mother. They would begin to inquire into the child's condition and Florence would offer an explanation. Asked whether such inquiries from outsiders worried Florence, she rather answers the question in a way which suggests that such people might have inculcated into her the hope that her child would eventually get well and this appears to have fuelled her belief that her child would eventually get well based on no physical intervention

Interviewer: *So, when they come here and see the state of the child and begin to ask questions, does that not disturb you?*

Florence: No, they always encourage me to continue taking care of the child and that he is going to get well. They think the child will get well so they continue to encourage me

5.3.3.2 Transcendent hope for cure

The transcendent hope for cure, a hope that was beyond the range of physical human experience, was a re-storying of their hopes of restitution underpinned or influenced by their religious beliefs, i.e., the belief that God could cure their children. With the construction of transcendent hope, it appeared that participants had acknowledged the limitations of conventional and alternative treatments and endeavoured to replace these with hope in God. This finding also extends what Frank describes usually as a cure in the restitution narrative model as it reflects a change in emphasis from “treatment” (alternative or conventional) to hope in God for cure.

Participants constructed a transcendent hope at the latter stages of their stories which was mainly grounded in their religious beliefs rather than biomedical ones. This type of hope was expressed by all participants in their interviews regardless of the heterogeneity that existed. All participants had affiliations with a formal or institutionalised religion and were active participants of religious activities at the time of the interview. They appeared to have the opinion that God has time for everything including the time that he would heal the children and until this happened, they would still continue waiting on God for this healing.

“God also knows when this child will get well. So everything is in the hands of God now. We know that with time, God would be able to heal him and our brother might improve and eventually walk”Leah (sibling)

For the study participants, the given rationalisation in their narrative concerning their hope in God for cure, is the realisation that all possibilities for cure or healing have been exhausted and the only final means for cure is from God.

“Now I have also come to know that there is no humanly possible cure for cerebral palsy so I always ask God in my prayers to heal my son. I have given everything to God. I pray every day, petitioning God to change my son’s condition and restore him to proper health” Arthur (father)

The extract above demonstrates a sense of discouragement and despair in both conventional and alternative treatment, but still longing for cure, the last hope of this father rests in the divine intervention of God. Though this father was still in continuance of physiotherapy treatment, his statement demonstrates that he may not have any hope in even the therapy his child was receiving.

This hope in God for cure appeared to mostly stem from religious readings. For instance, the practising Christians related this to instances in the Bible where some persons with disability who believed in God for a cure were healed miraculously.

“When you look through the Holy Bible, things of this nature happened. There were many people in the Holy Bible who had disabling conditions like this and couldn’t do anything to heal themselves until God intervened. So, a condition like this, you cannot do anything about it except God himself intervenes and heals the child”...Peter (Grandfather)

“The book of Mark in the Bible, chapter 10 verse 46 says that Bartimaeus was blind. His mouth and ears were functioning. When one day Jesus was passing by, he used his mouth to shout for help from Jesus. People tried to shut him up but he continued shouting. He kept on shouting until Jesus heard and healed him and that brought him the Joy of his life. Like Bartimaeus we know our child would be well with the help of God”.....Kennedy (father)

Normally, such Biblical happenings in which persons with disability were healed were usually testimonies for those who did not believe in God and therefore got converted to Christianity after being healed. Ernestina, a mother to a child with CP, seemed to be aligning her transcendent hope for cure to this fact by believing that her child would be healed by God and his healing would be a testimony through which many people would be converted to believing in God and she therefore continually clings to the transcendent hope of her child being restored.

“I tell him that God loves him and that his life is going to be a testimony to the whole world. I tell him to keep in mind that God loves him deeply. I tell him to keep in mind he will one day testify of what he went through as a child in front of a huge crowd and his testimony will draw many people to God. If this child stands in front of a multitude and testifies that as a child,

all his blood was drawn out of him and replaced with a different one and developed a condition like this but he still survived despite the bad condition he encountered afterward, it will be a great testimony which will make people understand that there is nothing that God cannot do”...Ernestina (mother)

However, there were some participants who endeavoured to justify that such transcendent healings are not only recorded in the Bible but could have real occurrences in life. Emelia, the grandmother to Heather, 5 years 3months old child with cerebral palsy, recalled a personal incidence in which she was miraculously healed by God through praying and therefore seemed to use that incident to justify her hope that God would heal her grandchild. According to Emelia, she had suffered from some sickness for 8 years and all biomedical and alternative treatments failed to provide any healing. She appeared to align her grandchild's incurable condition to what happened to her in the previous years and through that, justified her hope that her grandchild's condition would be cured by God in a similar way.

*“I have suffered some sickness for 8 years, but God saw me through and healed me. If I tell you what I have been through, you would even cry for me. Sometimes my whole body would swell up but by the grace of God, I am healed. Prayer can do everything. So, all my children also follow my footsteps. They know I have never forsaken God to do anything He does not approve of and they will never do that too. No matter how long it tarries, God's time is the best and He will heal the child at the appropriate time”
Emelia (grandmother)*

Demonstrating a transcendent hope in God to provide cure for the children, participants engaged in continuous personal or contingent religious rituals [prayers in Christianity and “Sallah” in Islam] through which they bargained with God for improvement and cure for their children's condition. They believe that through these religious rituals, God would provide healing for their children.

“We organise some prayer camps in the church I attend so when the times are due, I send him there to be prayed for. So gradually, God has listened to our prayers and the child is able to walk and talk a little” Abraham (father)

“Because of my trust in God, whenever I am doing “Sallah”, I raise my hands and pray to God to heal my child, restore his brain and make him walk. That’s how I have been praying for my son” ...Arthur (father)

Though participants demonstrated a transcendent hope for cure, this hope was also reinforced by the opinions of others. Such reinforcements were provided mostly through the opinions of religious leaders who regularly claimed that their children would be healed.

“I have been taking him for prayers [at different churches] till now. They tell us at such places that he would walk and talk. So always I pray to God at those centres to heal the child. The only thing they keep saying is that he will be able to talk. You know I don’t have spiritual eyes and spiritual ears to see and hear anything as they do. So, whatever they say, I believe. These are men of God and they are spiritual people, so when they tell you things like this, you cannot doubt it”. Mary (grandmother).

Mary’s statement demonstrates that though she has a transcendent hope in God to cure her grandchild, this hope is fuelled by the opinions of her religious leaders which she believes would never fail.

5.4 Conclusion

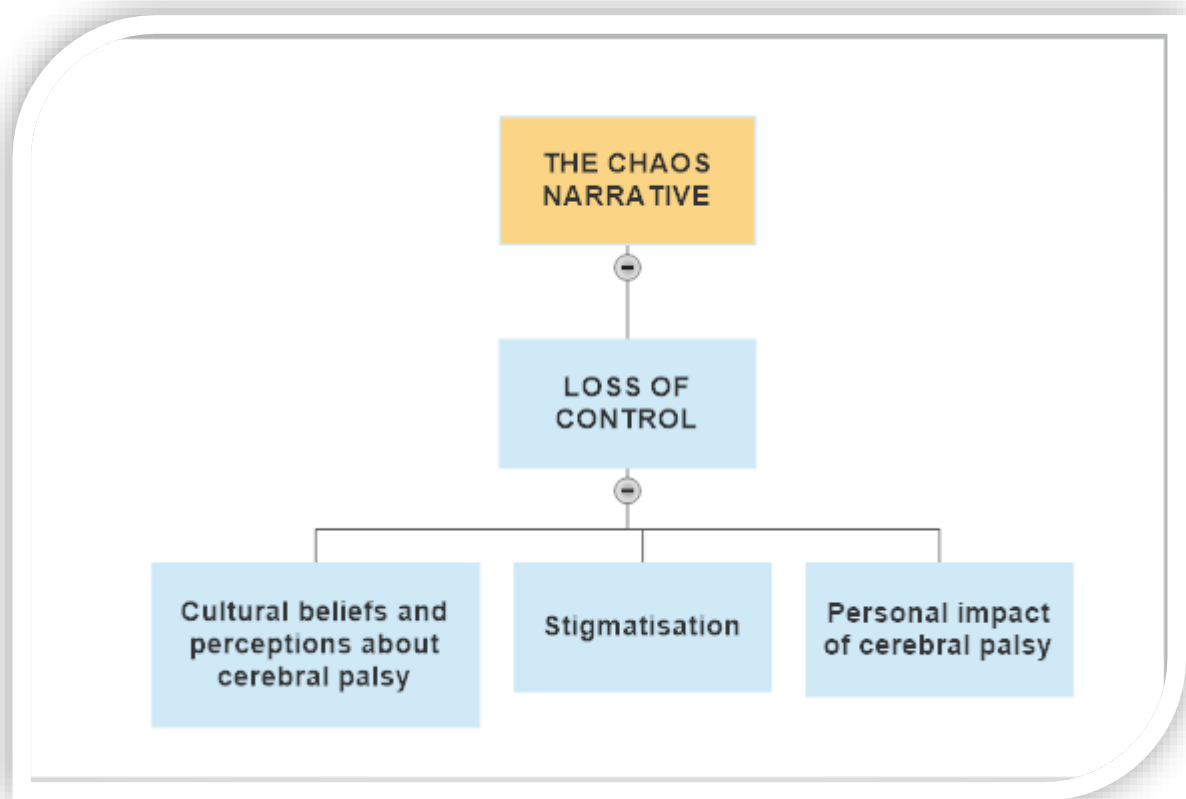
This chapter has demonstrated how the restitution narrative was enacted by all study participants. From the time of finding out something was wrong, till the time of the interview, participants still wanted restitution to occur for their children. Though the restitution narrative was intruded by other narratives, it never went away because interviewees always returned to the restitution narrative. When there seemed that all hope for restitution in biomedical and alternative healthcare was lost, participants still clung to the restitution narrative by expressing their hope for cure intransitively and transcendentally.

CHAPTER SIX: THE CHAOS NARRATIVE

6.1: Introduction to the theme

This chapter presents and demonstrates evidence from data with regards to how the chaos narrative was constructed. In the chaos narrative, *loss of control* was found to be the major theme. The *loss of control* theme is also underpinned by three sub-themes: *cultural beliefs and perceptions about CP*, *Stigmatisation* and *Personal Impact of cerebral palsy*. Figure 10 is a display of the chaos narrative, its theme and sub-themes

Fig. 10: A diagram showing the chaos narrative, themes and sub-themes



6.2 Chaos

The opposite of the restitution narrative is chaos. The plotline of chaos narrative imagines “life never getting better”, having no control over life and being at the mercy of the condition (Frank, 2013). The chaos narrative constructed by participants in this

study mostly demonstrated a loss of control as a result of living with a child with cerebral palsy

6.2.1 Loss of control

Mothers, fathers, siblings and extended family members told chaos stories that occurred periodically throughout their lives and mostly demonstrated a loss of control as a result of living with a child with cerebral palsy. The chaos narrative occurred earlier for parents than siblings and extended family members as they were the first to be made aware of the diagnosis of the children's condition and the associated prognosis. Despite the difference in time, the initial occurrence of the chaos narrative for parents, siblings and extended family members appeared to be associated with learning about the nature of the condition of cerebral palsy. Although all participants reported chaotic emotional experiences at the time of diagnosis and the period immediately following it, these were dominated by parents (fathers and mothers) who took these children to the hospital. For example, Nelson, the father of Felix, a child with cerebral palsy, described the reaction to the diagnosis of cerebral palsy and the biomedical explanation that followed.

"It was a big issue in the family. An issue of sadness. Looking at a baby who was so handsome and vibrant and later realising he's had this condition is indeed very sad. My wife could wail and cry the whole day due to the child's condition. She would refuse food most of the days. On my part, I didn't cry about the situation, but you would see me on many occasions sitting quietly in a thoughtful manner, with my arms supporting my chin, and one could realise in those moments that I was immersed in thoughts of my child's condition. It was a time of great sorrow. , It was a great traumatic period for my wife and me. My wife would cry until tears wouldn't flow anymore. It's sad and painful".... Nelson (father)

This quote from Nelson suggests an emotional experience underpinned by great disturbance, confusion, and uncertainty. At this point in their narrative, both Nelson and his wife typified the emotional response associated with the acknowledgement that something was wrong with their child and the subsequent diagnosis of cerebral palsy, portraying a consistency with the chaos narrative at this stage of their experience. For the parents who participated in this study, this period was

characterised by shock, grief and a profound sense of loss of control, which was consistent with the chaos narrative. The statement of Nancy, the mother of Geoffrey, an 8years old child with cerebral palsy, typifies this finding when the news of her child's condition was broken to her at the hospital during the period of diagnosis. The news of her child's condition, when broken to her, occupied her thoughts so much that she appeared to have lost control of her emotions and nearly endangered her life.

Nancy:

I remember when I was coming home from the hospital, on the day they first told me my child had cerebral palsy, hmmm

Interviewer:

What happened that day?

Nancy:

It wasn't easy for me to take it when they told me my child has cerebral palsy and explained the nature of the disease to me. The news came as a shock and I didn't know what to do about it. When I was told my child had cerebral palsy, I did not know when I descended the staircase to the ground floor. Before I realised, I had gone out of the hospital and was outside. You know there is a motorway in front of the hospital which one must cross if she wants to get to the other side. I was crossing the road without looking out for any approaching vehicle. When I came to my senses, a middle-aged woman had grabbed me and was pulling me to the pavement. I was nearly knocked down by a car. The horns of the car had honked thrice on me but I didn't hear of it till the woman who sells some porridge outside the hospital, grabbed me and told me what nearly happened to me. I looked back at the driver who had then stopped on the road and was looking at me in amazement and apologised

Though parents dominated the enactment of chaos at the point of diagnosis, siblings and the extended family members also constructed chaotic emotional stories during the period immediately following diagnosis when the nature of cerebral palsy was made evident to them. For instance, Mary's statement below portrays the emotions she felt when the news about her grandchild's cerebral

palsy was first broken to her. When the news about her grandchild's cerebral palsy was broken to her, it appeared Mary was greatly devastated and spent sleepless nights brooding over her grandchild's condition and expressed an uncertainty about the child's future, an action which caused the enactment of chaos.

"When I discovered my grandchild was suffering this kind of disability, I was greatly worried. Even sleep sometimes eluded me. I would lie in bed the whole night thinking about what would happen to her future".....Mary (Grandmother)

Enactment of chaos by siblings and extended family members also centred on how they witnessed a loss of emotional control from the parents of these children which in turn caused a loss of emotional control on their part. This is typified by Rita's statement below:

"My mother was always sad about the child's condition and was always in a sorrowful mood especially when she saw other children of her age walking and playing around and our brother had been diagnosed with this condition. It made her sad and it made all of us sad as well because my mother cried all the time".....Rita (sibling)

Significant about the chaos narrative as it became the foreground narrative was the blame cast upon the health professionals with a group of participants (4mothers, 2siblings, 3 extended family members, and 1 father) feeling that health professionals were potential contributors to the cause of the cerebral palsy either as a result of care during delivery or through medical procedures carried out shortly after birth. For example, Norman, the father of a child with cerebral palsy and Margaret, the grandmother of another child with cerebral palsy expressed a view that medical negligence by health professionals was the cause of cerebral palsy and therefore registered their displeasure over this supposed medical negligence. Norman further suggested that other medical professionals questioned the medical care received by her wife during labour and delivery. This, he considered, provided further evidence for potential medical negligence.

"This child was born at [name of hospital], so the doctors could have examined to find out that he had a condition like this. The doctors did not

do this when the child was born, and they rather asked us to send him home. I remember when the child developed this yellowish condition and my wife sent him to the hospital, the other doctors wanted to know from my wife which doctor attended to him when she was in labour. They wanted to query the doctor on what really occurred during delivery, but my wife didn't give the name of the doctor out. This makes me think that the doctor made a grave mistake during the child's delivery and it has resulted in this. My wife was scared that doctor may lose his job and license if she gave his name out" ...Norman (father)

"When she was about to give birth [child's mother], the midwife in charge had left the room and also instructed her not to push if she felt like pushing. This is somebody who has not given birth before and had no experience with childbirth. She told me the child came first with her head, so I guess the child was rather resting on her neck when her birth delayed. She asked the midwife why she was not allowed to push the child out and she replied that it is not done that way so she should continue lying at his back on the bed. I was very much disturbed because as a person who works to save lives, she shouldn't have done that. She should rather have had time for my daughter, talked to her in a friendly manner and pampered her because it was her first time. She should have also been with my daughter to monitor till the date of delivery. It was her first time so the midwife should have guided her through and what to do and what not to do. I was very disturbed when my daughter [child's mother] told me but I didn't want to say anything to cause any drama".... Margaret (grandmother)

Furthermore, relating to the perception that health professionals could be potential contributors to the cause of cerebral palsy through the performance of perceived inappropriate medical procedures after birth, Leah, a sibling living with her brother with cerebral palsy commented:

Leah:

I also think the blood given to the child at the hospital by the health professionals is also the cause of my brother's cerebral palsy

Interviewer:

What makes you think that the blood given to the child at the hospital was the cause of the child's condition?

Leah:

Why should a fresh baby's blood, whose system is not developed, be replaced with an adult's blood? Yea, the child's system could not cope with the blood given to him and has resulted in this condition. So, I will advise all health workers must be careful about any clinical procedures that they conduct for patients. The health workers should have let us know that they were going to change the blood of my brother and give him a new one.

Interviewer:

They did not inform the family?.

Leah:

No, they didn't

Interviewer:

So how did you feel about it?

Leah:

I was very angry that they carried on with the transfusion without informing any of the family members. Maybe one of us would have donated and this condition would have been prevented

Leah's brother, Jayden, who was 6 years old at the time of the interview, showed symptoms of jaundice a few days after birth. Therefore, medical professionals tried to treat the child's condition through the performance of exchange blood transfusion. The procedure was done successfully but a few months after the procedure, her brother was diagnosed with cerebral palsy. From Leah's interview, she perceived that this exchange blood transfusion procedure was the cause of her brother's cerebral palsy and blamed the health professionals who were involved in this process. What makes Leah's report interesting is the fact that Leah was a qualified nurse and one may expect that she wouldn't demonstrate negativity towards medical interventions done by professionals. However, it appeared as this was associated with her brother, she

emotionalised the reality of his brother's condition and blamed the health professionals as the cause.

The chaos narrative moved temporarily from being the dominant narrative to being a secondary narrative once biomedical management of cerebral palsy began and participants believed that the biomedical treatment could meet the hoped-for outcome (see chapter 5 section 5.5.2). However, as participants realised that the biomedical treatment would not cure the cerebral palsy, many participants reported moving to a combination of both alternative and biomedical approaches, with the hope that such complementary approaches would result in a cure, thus restitution again became the dominant narrative. Over time, there was re-emergence of the chaos plotline as the primary narrative as participants came to realise that the children's condition was not getting any better despite their efforts in seeking both biomedical and alternative help.

*"We have tried so many times to find cure for the child but anything we do does not bring any cure. We have tried several times to get some potent medicine to cure the child's condition but whatever we tried to do have proved futile with no expected results. It is not our wish that it happens this way, but it has already happened, and we cannot do anything about it"....
Peter (Grandfather)*

"I have attended physiotherapy for quite a long time now and herbalists have also seen my son's condition and have tried to treat him but to no avail, though there has been some slight improvement as I have already told you. Looking at how we have been attending physiotherapy treatment and the application of the herbs, in addition, by now there should have been a considerable improvement".... Arthur (father)

Chaos became dominant at this stage as participants felt they had lost control over the children's condition with regards to treatment or expectations of cure. Participants appeared to feel that there was no guarantee that anything would help again.

6.2.1.2 Cultural beliefs and perceptions about cerebral palsy and the loss of control

Cultural beliefs and perceptions about CP were evident in the talk of participants, which were strongly linked to the chaos narrative and the loss of control theme.

According to Frank, culture honours the restitution narrative that any illness can be cured but when restitution fails to be achieved, there is a tendency to demonize illness or attribute it to supernatural and mysterious causes (France et al., 2013, Frank, 1998, Frank, 2013) and it appeared that this was consistent with the chaos stories that participants told when restitution had failed. The chaos narrative appeared to be underpinned by the dominance of cultural beliefs that were linked to mystery, superstition, and spiritualism; participants felt that they had no control over these. Most participants expressed that the cause of the children's condition was difficult or impossible to understand and expressed a belief in the supernatural as the cause of their children's condition after both biomedical and alternative encounters had failed to bring about the restitution they expected.

"Yes, I think it is mysterious and strange because sometimes I ask myself, "why only him and why now?" I feel it is mysterious and strange because all the members of this family are healthy and strong and he is the only person with this condition" ...Leah (sibling)

These beliefs were narrated by participants who also referred to the presence of these beliefs in the communications and interactions they had with others.

"When my daughter was pregnant, she had a quarrel with one of the tenants who told my daughter that 'you will suffer when you give birth'. So, wherever we went, the pastors told us that it was what the lady told my daughter that has taken effect on the child. People opined that it could be that the lady is evil or evil spirits took advantage of what the lady said and have brought this condition to my grandchild" ...Emelia (grandmother)

To support a belief in the supernatural as the cause of their children's condition, some fathers described specific spiritual and supernatural happenings that supported their strong belief in mystery and superstition with regards to the actual cause of their children's condition. An example was that of Kennedy who claimed that God revealed to him and his wife that they would have a very healthy child, but the child's life was going to be very challenging. He narrated that the child seen in the dream was a healthy child different from the child they had in real life. This made the father speculate or perceived that some unknown person was mysteriously fighting against them spiritually to prevent the occurrence of what they saw in the dream

“What we saw in the dreams were mostly good, but it didn’t happen as we saw in the dream. In the dreams, we saw the child was going to be well and fine, but it didn’t happen. What we are seeing now is not what we expected in the child, so it tells us that something or somebody is fighting us to prevent the good things we saw in the dream from happening. We shall take whatever means, both medically and spiritually to make sure that what we saw in the dreams will come true.”

Kennedy’s view is a contextual thinking that is very popular and particular with Ghanaians. Whenever a Ghanaian experiences an overwhelming event such as an acute or chronic illness with an unexplainable cause, it is easy for them to conclude that an enemy or an adversary is working spiritually against them. They would feel that someone who does not want them to progress or flourish in life, is working spiritually to counteract their progress, the reason they might be facing such overwhelming circumstances. It appears this is what Kennedy is expressing when he stated that “somebody is fighting us to prevent the good things we saw in the dream from happening”.

With the failure of biomedical or local medicine to cure the child, the child was demonized, and their narratives were dominated by discussions of other ‘forces’ beyond their control influencing their experiences of living with the child with CP.

“Hmmm, you know there are two spiritual forces in this world, good and evil spiritual forces. So, when you think about the good, you also consider the bad or evil as well. I believe my brother’s condition can also have an evil spiritual cause. I believe evil forces are behind his condition”.... Rita (sibling)

Though these cultural beliefs with the underpinning mystery, superstition and spiritualism were constructed by all study participants, they were more dominant within the chaos narratives presented by the extended family, followed by fathers, and were least constructed by mothers and siblings. Perhaps, the frequent encounters with biomedical professionals by mothers during routine physiotherapy consultations and the exposure to formal education on the part of siblings had lessened their beliefs in the supernatural as compared to fathers and the extended family. The extended family members presented dominant cultural beliefs and experiences which were more

deeply grounded in superstition, mystery and spiritualism than any of the other groups and this is typified by Emelia's chaos narrative below which lay emphasis on the strong belief in mystery, superstition and spiritualism which was demonstrated by the extended family. As the interview progresses to the point where both biomedical and local medicine had failed to provide cure, Emelia begins to talk about her grandchild's condition being mysterious:

"What happened was that my daughter's husband had a car and a child of that lady, defecated near the car and afterward smeared the car with the faeces. This made my daughter angry and complained to the child's mother. The child's mother, strangely, didn't take it lightly and started insulting my daughter. My daughter also couldn't handle it, so she insulted her back and the lady, as a result, cursed my daughter with those words. I also strongly believe that the lady had been contracted spiritually to afflict my grandchild and her mother and the only way that lady could execute that spiritual contract was to do it through the act in which her son defecated and smeared it on the car"...Emelia (grandmother)

From the above quote, Emelia believes somebody cursed her daughter and as a result, it affected her grandchild, resulting in the child developing cerebral palsy. What was interesting is when Emelia mentions that "somebody had been contracted spiritually to afflict her grandchild". In explaining this, Emelia unpacks a great deal of supernatural and spiritual beliefs which could be the cause of cerebral palsy and any disability in general, as narrated below:

"Mm, sometimes it all depends on the family one comes from. Sometimes people in the family or outsiders can even find out spiritually about the future of the child and if they see that the child would be a successful person in the future, they would try to destroy the child by such conditions. Secondly, sometimes, people who are childless can also consult spiritualists to help them give birth and they are able to give birth and usually, such children do not become normal people for the whole of their lives. You see them drooling everywhere. Sometimes too, when you see a sick person or a person with disability in the streets and you tease or mock her, that person can also destroy your children with the condition she suffers from. Yea,

mocking a person living with some sort of chronic condition, can have an effect on your children. Sometimes too it is as a result of what you say to someone that makes him hurt and he also would curse you. If it happens this way, such conditions may also come to your children when you give birth”.

Finally, Emelia completes her story by sharing an incidence which she appears to use as a piece of evidence to demonstrate that the supernatural has a role to play in chronic conditions

“I know of one woman like that who it is said was complaining to a friend that she needed a child badly. It is said that the spot they stood was where a drunkard once stood and died so that drunkard’s spirit was still there. The spirit of the dead drunkard, therefore, heard what this woman was saying and entered her womb. The woman was finally able to give birth to a child but when you see the child, the child had the appearance of a drunkard. That child could defecate about ten times in a day, so the woman finally took her to see a spiritual lady pastor who told her the real cause of that. Finally, through prayers, the child died and now that woman is free. So, as health professionals, you must be very careful with how you treat people. Spirits can turn to humans, come to you with their children having a condition like my grandchild. You must be careful to treat every child the same way, don’t discriminate or love some children more than others. If you do this, their parents who may be spirits would cast such conditions on your future children too”.

Emelia’s example above highlights the extent to which the extended family used their belief in the supernatural, mystery and spiritualism to justify the cause of cerebral palsy after all attempts to remedy the situation had failed to produce the desired outcome. Consistent across the stories of most of the extended family members was the conceptualisation that the child with CP had a great destiny and “some evil persons” had brought the CP on these children in order to thwart this great future from being accomplished, a notion which supported the views of some members within the other heterogeneous groups and further deepened the demonization of illness perception among participants

“And I believe it is because he has a great destiny that is why maybe someone has given him this disability spiritually”...Mary (Grandmother)

“We thought that some evil persons who know that this child has a bright future had brought the condition on the child. We were very sad about it”...Portia (Aunt)

“Oh yea, we all know that the child would be a very great person in the future. God has personally spoken to me in a dream that the child has a great and bright future. There is this proverb which goes that “everyone hates the one wearing a feathered hat”. There is something spiritual about it and we are praying to God to rescue this child from the hands of evil people”.....Samson (Grandfather)

From their narration, it also appeared some of the extended family members had encounters with others who also reinforced their belief that some evil people had caused the children’s condition.

“Such pastors attribute the cause of the condition to some witches in or outside the family who does not want the welfare of the child or who wants to disgrace the family”...Natasha (Grandmother)

6.2.1.3 Stigmatisation and the loss of control

Societal opinions of the children appeared to manifest itself in stigma; which appeared to lead participants into further chaos. Participants reported that people they came across opined that their children were not human but rather were originated from water bodies (There is a general belief in Africa that there are spirits or demons that reside in water bodies who are able to give children to people when consulted). The children were therefore demonised by society.

“Sometimes many people say the child is from a river. They call him “nsuoba” [child from a river]....Portia (grandmother)

“Someone had told me this before, one of my friends. Whenever I go to school, the friend I told you about earlier, who I said gossiped about me, used to tell me that my brother is not human, for the simple fact that he is not walking. She said such children are normally from rivers so when you

send them to a riverside and leave them there, they swim away into the river and vanish. She even suggested that I tell my parents about this so they would get rid of him but I told her I can't tell that to my parents and I don't even believe what she was saying".... Mildred (Sibling)

This narrative was dominated by the feeling that those describing the children in this way lacked knowledge of the condition, were ignorant of the biomedical management strategies and saw the killing of the children as the only solution.

"Getting rid of the child is what many people recommend, and they don't know about the remedies and solutions that are in place to help these children" Kennedy (father)

From the reports, societally constructed misconceptions about the children were generally rejected by the family, but it, however, appeared that within the family, the extended family was however concerned more by societal opinions which were manifested through stigma and appeared to have accepted the popular societal opinion of getting rid of the children. The extended family, therefore, played a dominant role in further demonizing the condition of the children within the family after both biomedical and alternative approaches of seeking help for the child had failed and when societal opinions had begun. The extended family identified further with the "strangeness" of the child's condition, attributing it to demonic or evil forces and even within some families, strong and ruthless suggestions were made by extended family members to the parents of the children, with regards to terminating the life of the children. Parents, therefore, felt a loss of control over the opinions of the extended family members whose beliefs were embedded in mysterious, demonic and cultural rituals. These suggested that terminating the life of the child was the only means to relief. The parents all spoke of rejecting these explanations and solutions, but this led to family tensions and family breakdown within some families reinforcing the chaos narrative. Abraham typified this by narrating an incident that occurred in his family. From the onset of cerebral palsy to the period of diagnosis through to the time when Abraham's nuclear and extended family realised there could be no cure for the child with cerebral palsy, Abraham and his wife faced an opposition from the extended family to terminate the life of the child. seeing it unlikely that there was a cure for cerebral palsy, Abraham and his wife were asked to engage in some mysterious

cultural rituals to “get rid of” the child. The quote below highlights Abraham’s predicament

“She [child’s grandmother] pestered me and my wife, her own daughter, to get rid of the child. His grandmother showed me the exact place where children like these are killed. Yes, it wasn’t easy for me. It was me and my wife against her extended family. The child’s uncles all rooted behind his grandmother that I should get rid of the child. She showed me what things to buy and give to the witch doctor so he could use them to perform some rites to kill the child. I was told the witch doctor will tell you to buy some kinds of stuff for the rites and these include gun bullets, alcohol, eggs, and many other things that I don’t remember. So, you will buy all these things and send them to the witch doctor on a scheduled date. I was told after sending the things, the witch doctor would perform some rites and the child will die quietly at home. Yes, I’m told the witch doctor fires a gun into some water body and that will kill the child quietly. Firing the bullets into the water means that the child was gotten from the water so if the water is fired with bullets, it kills the child spiritually. It is quite mysterious. Before you will realise, your child is already gone”.

Abraham and his wife resisted the pressure exerted but this led to family tensions and the breakdown of the relationship between them and the extended family which further enforced the chaos narrative.

“My mother-in-law initially put pressure on my wife to go and kill the child when I was in the city and that resulted in a fight between the two. I was then called by mum-in-law for a family meeting. I came here and she told me the same thing, to go and kill my child. I supported my wife that we were never going to do such a thing, so we stayed away from my wife’s family house for almost a year. There was a time a severe fight broke between me and my wife’s family, so it brought some loggerheads between me and them. For one good year, I did not step a foot on my wife’s family house. My wife was not in support, she never supported them. Her family members were not talking to her either. There was even a time my wife and the child

had to relocate to my place due to the hatred and insults from her family members”

Arthur reports a similar incident when it became apparent that there was no cure for cerebral palsy. Arthur was asked to bring his child to their hometown in the north where most of the extended family members (the child grandparents, uncles and aunts) lived. Sensing this could be the extended family’s plan to get access to his child and terminate his life, Arthur refused to go, and this also led to further chaos as it severed the relationship between Arthur and his parents for a very long time and their relationship had not being resurrected during the time of this study.

“So, my parents even stopped calling me because I didn’t send the child to the north. They have ceased calling me. Since I have been refusing their request, they have also refused to call. I can say it’s been a long time since they called me”.... Arthur (Father)

In one family where the nuclear family lived alone, it was reported the extended family members abandoned the parents and siblings of the child with cerebral palsy as they refused their demands to get rid of the child, this is typified by Leah’s statement where she describes that the parents and siblings of the child were expecting the members of the extended family to have supported them financially as they were facing hardships. However, it appeared the extended family did not want to have anything to do with them since they had decided to keep the child with cerebral palsy

“The other family members in the extended family have also abandoned or rejected us the nuclear family members and so all the problems fall on us alone. They don’t even visit us let alone supporting us with something they have. So, it is we the siblings and my parents alone caring for the child. None of the extended family members have visited us since the child came into this family”

Stigmatisation in this study appeared to manifest itself in two ways: the experience of stigma from close neighbours and stigmatisation experienced from the larger society. Close neighbours were normally tenants who shared the same rented accommodation with participants. The rented accommodation was normally ‘compound houses’ with

shared kitchen, baths and toilet facilities. These are called compound houses because they are buildings with large shared compounds that house many families (see section 1.1.8) .With neighbouring tenants sharing a common compound, it is usual and common for families living in such houses to interact every day with each other and this normally triggers friendships and cordial relationships among tenants. Study participants, living in such compound houses, reported how they were stigmatised by neighbouring tenants after giving birth to a child with cerebral palsy. Typical of Betty's story, a mother living with 5 years 3months old child with cerebral palsy, was how she had experienced stigmatisation from her neighbouring tenants in a compound house. Betty had previously lived in a compound house but had moved out of this house with her child to live with her parents in another compound house, due to the stigmatisation meted out by the tenants towards her and the child with cerebral palsy. However, she experienced the same stigma when she moved to her parents' compound house. From Betty's narration, it appeared her neighbouring tenants portrayed the misconception that cerebral palsy was contagious and would be transferrable to their children should they associate with Betty and her child.

"The children in the house I lived in did not want to even come near the child and play with her. They avoided her. It was only her brother who played with her. I told you I was in a different house before I moved here. In that house, I noticed that people started feeling that when I come near them, my child's condition would affect their children, so they did not want me to get near them. Sometimes you would want to send some of these children on an errand and they wouldn't even come to you. I felt their parents have warned them not to get near me. Yea, they wouldn't want their children to get near me to contract my child's condition. So, if I wanted to buy something from outside, I had to strap my child to my back, walk outside and get it on my own or sometimes I would send my stepson to go get it for me. So, I totally stopped sending any of the children in the house. It got to a time that I only exchanged greetings with people in the house. I thought it would be better when I relocate to my mother's place but the same thing is also happening here".....Betty (mother)

Florence also narrated a similar story about how her neighbouring tenant in the same compound house, stigmatised her. According to Florence, she suspected her

neighbour's child of showing signs of cerebral palsy and therefore suggested to this neighbour to seek medical opinion. However, this neighbour, instead of seeking biomedical help as recommended by Florence, spread rumours around the compound to other tenants that Florence had mysteriously transferred cerebral palsy from her child to the neighbour's child, causing the other neighbours not to associate with Florence and her child. Florence and her family were therefore ostracised in this compound house.

“There was also a lady who lived in this same house with me, her room was next to mine, who had a child like mine, though my child was older than hers. Looking at her child, he was showing signs of cerebral palsy. At his age, the child couldn't talk, nor walk, and his hands were very stiff, so I advised the lady to go to [name of hospital] for diagnosis and treatment. And what the lady did was an eyesore. The lady didn't take my advice but rather told other tenants in the house, who later came to inform me, that I have sought the services of a fetish priest and have transferred my child's condition spiritually to her child. The neighbours, therefore, started withdrawing gradually from me and my family. I became very sad when I heard this, I thought I was helping her but she rather thought I had transferred my child's condition spiritually to her child. Her child was three years old but couldn't talk nor walk, hands were very stiff, and couldn't even eat on his own. He couldn't walk and would be dragging his bottom on the floor when he tries to move, so I advised her mother to take him to the physiotherapy unit, but he rather refused and said such a painful thing behind me. Hmmm, when your child has a disability, you hear so many things from peopleFlorence” (Mother)

It was also common among participants, especially parents, to experience stigma in public situations such as outings and public gatherings. It was at such public places where participants thought their competence in handling children who are physically dependent would be unfairly judged. Embedded in Ernestina and Kennedy's statements below, is this finding.

“Exactly. Wherever I go with this child strapped at my back, his neck keeps on dangling at my back and it makes people shout at me. Some people go

like: “why have you tilted the child at your back?”, “can’t you see you will hurt the neck of your child?”, “haven’t you seen your baby is falling”? At times, they even insult me and they think I deliberately don’t handle my child well”....Ernestina (Mother)

“Sometimes I wish to also move out with my child but when people see us, they talk a lot, they go like, “why do you have to carry a child of this age”? “Your child’s neck is dangling, please try to stabilise it”, you see? So, some of these comments are heart-breaking. The person making the comments is not aware of what is happening, so he thinks you are not serious about taking good care of the child. Comments like, “is the child still not walking?”, “Has the child been able to sit?”, “has the child started schooling”? Such comments make you get worried and you ask what at all is happening to your life”.... Kennedy (father)

Kennedy and Ernestina were typical of the parents, in feeling that society was too critical of their ability to care for their children. It appeared they felt that they had no control over the opinions of others during such encounters. Even for Kennedy, from the first line of his statement, it appears he has restricted his social life to avoid these potentially disturbing public encounters. Another participant, Duncan, who had experienced unfair public criticisms also made reference to this.

“It is mostly the members of my church that usually say such things. Sometimes I would bump into them saying such kinds of stuff and I would give them a reply, yea, they don’t say it to my face. They do it secretly, but I catch them many times”.... Duncan (Father).

Society also stigmatised participants by demonstrating abusive behaviour to the children in the presence of their parents. Such social stigma was significant in the stories of parents as they felt they had lost control over others' opinions towards their children and which also resulted in their own loss of control over their emotions in such encounters. At such times, they had to vehemently react to cultural opinions about the child, further reinforcing the chaos narrative. This is identified by the quote below.

“Sometimes people even insult him in my presence, “sick and foolish boy with no head”. It’s so painful and sad when people verbally abuse my child like this. “Foolish boy with a deadhead”. When I hear them say these words

I tell them “my foolish child is wiser and intelligent than you”. I remember one day I heard a married man insulting him that he was foolish. I angrily responded “look here man, it’s fine my child is foolish, but he is more responsible than you. Mark it on the wall, by the time the child reaches your age, he would have built a house for himself, my sick child is more useful than you”. What I said made the man silent and people who had gathered at the scene laughed and hooted the man” ...Nelson

“I was very sad and angry at them for saying such a thing about my brother. Why must my brother be sent to the riverside to be killed? It would be left with me alone if my brother is gone. So, I was really very angry at them”...Lisa (sister)

Stigmatisation was further evident in the experiences of participants as it led to the concealment of the children from the public for fear of being continually stigmatised by society

“Ooh, no! no! Many people have not even seen the child’s condition. The child is always in the house or indoors. No one has seen that we have a child like this in the house...Natasha” (Grandmother)

“The mother even used to hide the child indoors. If the child doesn’t come out, you wouldn’t notice the child had any condition”. ...Portia (Aunt)

6.2.1.4 Personal impact of cerebral palsy

It appeared that from the point of diagnosis and the point where participants realised that both biomedical and alternative remedy had not helped enough to provide the remedy they expected, through to the time when others became involved in their lives and shared their opinions about the children’s condition, the chaos story appeared to be in some sequential order. However, as the chaos story progressed, it became an anti-narrative as it was told in no sequence or order and this finding was also consistent with the chaos narrative of Frank. (Frank, 2013). Participants demonstrated that the persistency of the children’s ill health brought about job problems, anxiety about the chronic nature of the condition, loss of income leading to financial hardships and an inability to fulfil family responsibilities on the part of parents. Within the experiences of participants, the chaos stories occurred prominently in certain

situations where their stories did not flow, and participants interrupted themselves. This mostly occurred when participants spoke of life difficulties. These life difficulties which underpinned this sub-theme, are explained in the subsequent categories.

a) Lost opportunities

All participants described the children with CP as mentally and physically dependent and were concerned that this was likely to deny these children societal opportunities and the ability to fulfil their lives in all aspects, a situation they had no control over. Participants perceived that gaining mental and physical independence was directly proportional to the chances of the children accessing these opportunities.

“Hmmm, I have seen that..... the reason we have not enrolled him in school yet is, I know his brain does not function properly, so it would be difficult for him to learn at school when he is enrolled. Again, he cannot walk and that would also make schooling difficult for him. The third reason is that there would be no one around to take good care of him when he is in school. These are the reasons why we have not enrolled him in school yet. He cannot walk nor talk and putting him in school wouldn't be pleasant. He should be walking and talking by now considering his age, but he can do none of these. This condition is likely to prevent my dream of seeing him through school to the highest level possible and to also enrol him in the Islamic schooling system where he could learn the holy Quran and the Islamic doctrines to become a “Mallam” Arthur (father)

It appeared there was a concern shared by participants that societal institutions also contributed to the lost opportunities for these children by neglecting societal inclusion for the children with cerebral palsy. They felt that they have no control over the exclusion of their children. These concerns over lost opportunities was a significant finding as it led participants to express no hope of their children having a fulfilled life and uncertainty towards what the future would bring, a finding which further plunged interviewees into chaos.

“I remember one of the doctors told us that such children grow to become important people in the future, but I am in doubt of what the doctor said. At

his age, this child cannot sit, cannot walk nor talk and neither can he use his hands to touch anything. How can he grow to become an important personality in such a condition? I am uncertain about his future, to be honest. Only God knows about what this child would become in the future. Can anything good come out of him? If he had gained some independence, then we would have had some assurance that he would become somebody important in the future but now he is totally dependent and that makes us doubt that he would become an important person in the future. When he is lying on the floor, he would remain at the same spot until you turn him. He cannot even turn himself so how can we be sure of his future?" Portia (Aunt)

While concerns over lost opportunities for the children were constructed by all participants, loss of control over own life plans and opportunities was a narrative that was dominated by the parents as described by Abraham and Harriet. For Abraham, it appeared he had plans of building or buying a property for himself through the earnings from the lucrative job he once had but having a child with cerebral palsy had disrupted these plans, a situation he had no control over.

"At first, I wasn't staying in this town because I was working in the city. All my siblings are in the city working so I was also there working as well but due to my son's condition, I had to leave a very lucrative job in the city and relocate to this town and be with him. Since I came here, I have never gone back. Had it not been my child's condition that made me left my job to take care of him, I would have built my own house by now"....Abraham (father)

Harriet, already educated to Master's level, had planned to undertake further postgraduate studies in forensic linguistics with the aim of joining the security forces as a forensics expert after completion. Having a child with cerebral palsy changed this life course forever, a situation she could also not control.

Harriet:

I read peace and development studies for my first master's degree and majored in linguistics. So when I was in the first year, I wanted to go into forensic linguistics so that together with the development studies I could go into the security forces to work with the department that looks into voice

tapes to find out whether something was true or not. That was the area I wanted to go into but I realised when I gave birth that it wouldn't help me

Interviewer:

Why did you think it wouldn't help you?

Harriet:

I realised the pressure and demands of that field wouldn't let me have time for the child. I read French for my first degree so my motive was to join the security forces in the area of peacekeeping and international relations but I realised with this child in my life I may not have time for her if I continued with that aspiration, because that area of work demands a lot of travelling. Moreover, if you leave her in the care of someone, she might not have the patience to treat the child well like I would do so that was why I stopped

While the narrative of lost opportunities for themselves was dominated by parents, there were participants from both the sibling and the extended family group who identified with this construct.

"I wanted to stop working at a restaurant and start trading in foodstuffs. I wanted to do bulk purchasing of foodstuffs and sell them to restaurant owners and other people who may be interested in buying. I was at the brink of starting this business when this child's condition set in. I had even saved some money to invest in this business, but all the money has gone into the child's care and none is left".... Margaret (Grandmother)

It is a common practice in the Ghanaian community for one to leave children with their parents in order to have time to concentrate on their jobs. Rita had planned to leave her children in their grandmother's care so she could concentrate on working. However, Rita's plans failed to come to pass as her brother had cerebral palsy.

"Ooh, my plan was to leave my children in the company of my mother so she would be able to care for them and I could also get time to concentrate on my job and be free to do other important things as well but this is the case that I have a junior brother with this condition who is entirely dependent on my mother and even the rest of the family members as well

so I cannot leave my children with my mum to take care of them. She has got enough problems already to handle, yea. So that was the plan I had in mind but it did not come to pass because of my brother's condition that has made him so dependent. My mother has got enough problems already with my brother so I cannot add my children to hers"...Rita (sister)

b) Financial burdens

The financial impact of living with a child with cerebral palsy was also raised by participants in this study, although this was more dominant in the narratives of parents

"Yes, that's the problem I am going through [financial hardship]. Her father is also facing financial difficulties. When we had not given birth to this child, my husband had his own taxi cab and it brought him lots of money for our daily upkeep but since this child came, we have spent a lot of money on her to the extent that her father had to sell her car to raise money for her hospital bills and for our daily expenses on food and house bills. So now he has no taxi of his own. He is driving somebody's car now and he is not making any good amount from it. So we all depend on the small amount he makes".... Betty (mother)

Nine out of the ten mothers in the study had been forced to give up their jobs to take care of their children. These mothers had no formal education and hence engaged low-skilled jobs related to selling food items and other groceries in makeshift shops and also by hawking along the streets, itinerant trading in second-hand clothes and other low-skilled jobs which were both unstable and not lucrative. Thus, with the children with cerebral palsy in the family, these mothers could not continue with these jobs and had to quit their jobs to cater for their children and hence the financial stress in the family mostly fell on the shoulders of their husbands

"One other effect has got to do with finances. Because of his condition, I no longer get enough money to help my husband cater for the children because I have terminated my work. So, money for daily expenses has become a problem".... Nancy (mother)

"Apart from his father supporting the family, we don't receive any financial support from outside. Nowadays his job that he does is not bringing enough

money, so we are struggling a lot financially. When I and the children need something, we solely rely on our husband and sometimes, he would tell you, "oh! Florence, I don't have even a penny on me". Our financial situation is very sad....Florence (mother)

"We try, we just try to keep them going all by what the father brings to the table. If the father does not provide, I have nothing to offer since I am not working.... Lydia (mother)"

As the burden of catering for the family fell mostly on fathers, they reported the pressure they felt as a result of becoming sole breadwinners in the family and the loss of control they felt over their families' financial situation and as a result, life in general. Duncan's statement is a typical demonstration of this finding.

"What worries me is the financial crisis that I still find myself in .His condition has plunged me into such a financial debt that I never even imagined. I first rented an apartment where the family was living together but due to financial hardships, I couldn't continue with the rent so we had to move to her family house. I would be able to make ends meet, had it not been this child's condition"...Duncan (father)

From Duncan's quote, it could be discerned that the financial problems the family faced had stretched to the extent of making other elements of life such as housing or accommodation, more difficult. Furthermore, having to pay bills regularly at the hospital and at alternative treatment centres for many years to date for their children was one of the major contributors to the financial stress that fathers passed through.

"Yes, it has lots of effects on my finances. I have spent and continue to spend a lot on him. I spend a lot on him especially when we send him to the hospital. The bills from the hospital are very high. I remember when he was first sent to [name of hospital], we spent about 5000 Cedis on him before he was discharged. And when he goes for physiotherapy every month, I spend money too. I spent about 5000 Cedis during his first admission only. I paid hospital bills every morning when he was on admission. I would go to the hospital every morning to pay this money. Every injection they gave him had its own cost. It wasn't easy for me. Looking at the money I was paying every day, it wasn't easy for me. I have

been spending money on him to date. I spend more on physiotherapy too. I have been paying so many hospital bills and the child is not even getting well. If I am to count the money, it would be enough to take care of this family for a long time” Norman (father)

“At the hospital, they would give us some drugs which are very expensive, and I struggle a lot to pay for this. Sometimes people would recommend some herbalist to me and in a bid to help my child get well, I would look for that herbalist and seek treatment from him for my child. Seeing these herbalists demands huge amounts of money. Some of them can charge 400 Cedis, 300 Cedis, 450 Cedis and sometimes even 600 Cedis but I would still pay because of the hope of seeing my child get well”.....Arthur (father)

When fathers reported about paying for healthcare services, it could be that either they haven't registered their families under the National Health Insurance scheme (see section 1.1.5), the hospital does not operate with the scheme or the conditions of their children are not covered at the hospital they attended. Herbal consultations, on the other hand, are strictly cash and carry. For fathers, whose children were in school at the time of the study, another contributing factor to the daily financial stress was expenses on school and in paying for fees. The money paid at such instances were deemed as very expensive due to the special needs of the child and the fact that the child had to be enrolled in a private institution since they were not accepted in public ones.

“Attending that private school is financially challenging. You buy medicines worth 700 Cedis every month, you will pay almost 500 Cedis to the school every month. So almost two-thirds of our salary is already gone before we receive it, how can we survive on the small one-third left?” Kennedy (father)

These financial burdens had a significant effect on fathers because they reported many instances where they were financially hard-pressed, found it difficult to provide for their families and had to rely on borrowed money before being able to provide for their families. Fathers, therefore, felt a loss of control in providing for their families and a subsequent loss of identity. Living on loans from friends to keep up with the financial

demands of the child and the entire family were common among these fathers and was described as a challenge to self, a description that reflects the narrative of chaos

“I find it difficult borrowing money from people but sometimes I have no option than to ask them for a loan. Some would tell you “I don’t have money” others would say “I have some money “and they would loan it out to you. Sometimes I borrow bits of money from different friends, put them together and add the little I have before I could buy the medicines for the child. So, my child’s condition has put me in a bad financial situation, especially at this time when I am not gaining enough from my job. Money for the daily upkeep of the child has become a very huge problem because what I saved has already been spent on the child and the proceeds from my job have also gone down”Arthur (father)

The financial burdens also appeared threatening to the relationship between fathers and their wives and for one father, his financial situation had escalated to the extent that he lived in fear of his wife cheating or divorcing him, a typical chaotic scenario.

“His condition has plunged me into such a financial debt that I never even imagined. They say if you don’t have money, your wife may even cheat or divorce you unless you meet a woman who fears and worships God. So, when my wife becomes upset because of the financial difficulties, I make sure I find a way to calm her down, by talking to her softly and sweetly or pampering her so as to prevent any marriage breakdown. Sometimes, when she gets angry with me, I would kneel down to apologise to her or would tell my mother-in-law to talk to her for me so that she would calm down. I will also plead with you, since you have come here, to also speak to my wife for me. Please advise her to have patience with me. Tell her I am facing a lot of financial difficulties and I know, since you are from the hospital, she would listen to you. I really love my wife and I don’t want to lose her because of financial difficulties. Sometimes I am afraid I may lose her due to the quarrels she picks with me whenever I am not able to provide. I don’t want my marriage to land in a divorce because of these financial difficulties so please speak to her on my behalf” Duncan (father)

The financial hardships reported by fathers also had a significant effect on siblings, especially those who were still in school, as they felt that they were losing control over schooling. Embedded in Lisa's statement is this finding.

"His daily upkeep is very high and it is causing a toll on my parents which is also affecting us in return with regards to our schooling. At the moment, our parents are struggling to provide for us and it is really affecting our schooling"....Lisa (sister)

The extended family also further contributed to the chaos narrative due to financial hardships faced by parents, as they felt that they could not do anything to help these parents come out of such financial hardships.

c) Physical support

Even though most parents had other children and some extended family members (grandmothers, grandfathers, Aunts) staying with them, mostly, these children were students and could only help with taking care of the child in the evening when they had finished school or during vacation periods. Most of the extended family members also had job commitments to satisfy and could not do much to support the parents physically. Where the extended family members were not working (Grandmothers, grandfathers), they were often elderly people who felt they did not have the strength to handle all care needs or the daily care needs of the child. Further chaos was therefore caused by the lack of support available to parents and furthermore experienced by those who themselves were restricted by their abilities to contribute and the burdens placed upon them. These extended family members enacted the chaos narrative as they felt they had little control over the situation. Emelia's story typifies this narrative

"The only thing is that I cannot take care of her entirely because I am not strong now. If it was at first, I could have adopted the child while the mum still continues working on her job but now I cannot because I am a bit old and weak. Sometimes I get sad over the fact that I have no strength to take care of the child. If I was strong enough, the mother would have also been free to find jobs to do to support her husband in taking care of the child"....Emelia (grandmother)

In families where the grandparents could offer some physical help to support the parents, they felt that they were losing control of their own health due to having to help and also due to their old age.

“Hmm, yea, sometimes I experience waist and general body pains and I believe they are as a result of carrying this child almost every day. Sometimes too I feel very weak.... Margaret” (grandmother)

The situation, therefore, demanded that one of the parents stay home to cater to the needs of the child and this mostly fell on the mother. The only mother, Harriet, who was still working at the time of the interview to support her husband in the family was an educated mother who was working as a graduate teacher. Even for Harriet, though her child’s grandmother was helping with physically supporting the child so she could attend to her education job, Harriet still had to take her child to school sometimes and care for the child whilst teaching and this created a great deal of inconvenience for her in her work environment as most of her colleagues began to raise complaints.

“At first, when the headmaster called, he told me there were reports that I was bringing my child to school and that it was against the law.... I was forbidden not to take her to school with me. So I went to [name of hospital] to get an official medical note for the headmaster so he would understand and allow me to bring my child to school. So, when I went to the hospital, the doctor just took the child’s folder and asked me to come the next day, but the doctor rather came to the school himself to explain to the headmaster unknown to me. The headmaster then called to tell me that the doctor had come to school to explain things to him so I am allowed to bring my child to school but there were other teachers who were not in support. They wouldn’t tell you directly but sometimes during staff meetings, some will make passing comments like, “some people are allowed to bring their children to school while others are not allowed”, you see? Those kinds of comments”. Harriet (mother)

In families where parents had bought some assistive mobility devices like wheelchairs and crutches for these children, they felt that the children were still not independent as they still required someone to assist them with moving these devices.

“Even when they are using crutches you must be near to help them with other things and when they use wheelchairs, you have to still be there to push them around and that too is very difficult, so they don’t really become independent”...Betty (mother)

“It wasn’t easy buying that walker [wheelchair] for him, and even after buying it, he still must be assisted before he can walk with it. I would have gotten time to do other things if he was able to walk with the walker [wheelchair] on his own, but this is not the case”...Lydia (mother)

6.3 Conclusion

This chapter has demonstrated how the chaos narrative typology was enacted by participants. The chaos narrative was enacted when participants gained a diagnostic label to the children’s condition and biomedical explanations were offered. Again, chaos became the dominant narrative when participants realised both biomedical and alternative healthcare had failed to provide the desired or expected cure for cerebral palsy. After this realisation, the enactment of the chaos narrative throughout participant narratives was underpinned by cultural and societal beliefs, stigmatisation, and personal impact of cerebral palsy which included lost opportunities, financial burdens and physical support. The next chapter will consider the quest narrative and a demonstration of its enactment by study participants.

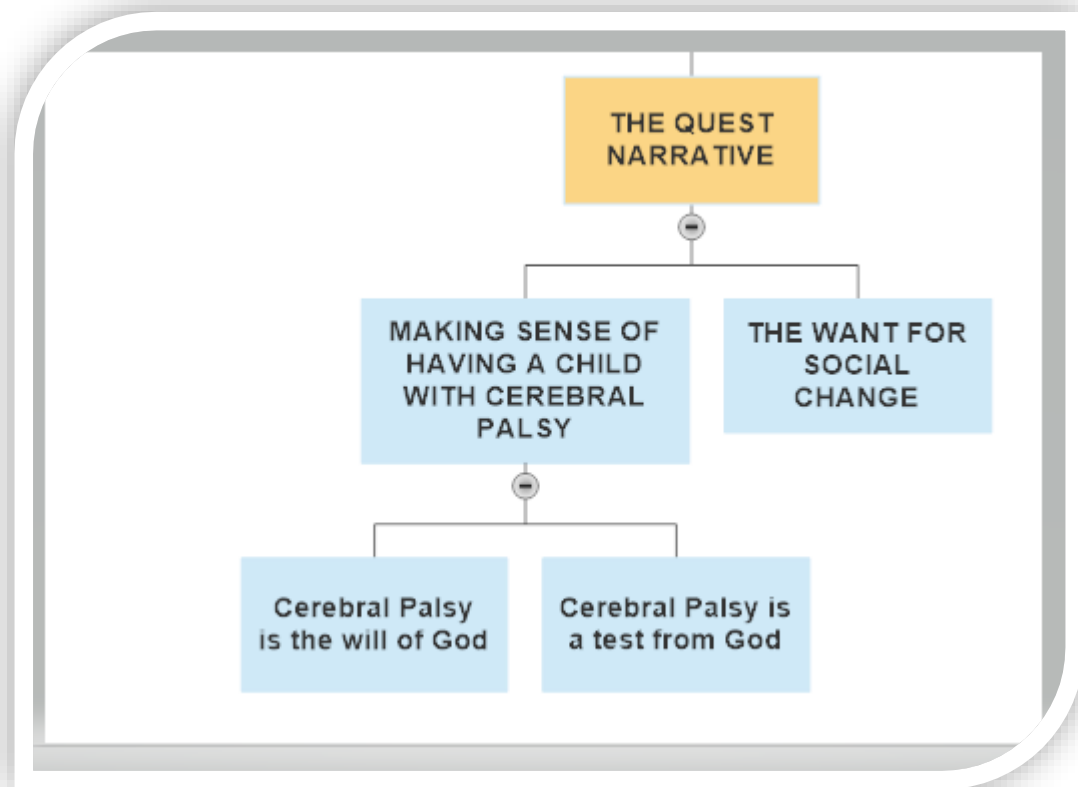
CHAPTER SEVEN: THE QUEST NARRATIVE

7.1 Introduction to findings

This chapter will present the Quest narrative demonstrating how this narrative was also enacted by study participants from their experiences of living with children with cerebral palsy. Of the three forms of quest proposed by Arthur Frank (1995), study participants constructed the *auto-mythology* and the *manifesto* but not the *memoir*. The quest narrative gives a voice to the teller to narrate his own story of the experience. Restitution and chaos do not provide the avenue to hear the voices of participants because the “active player” in restitution is the remedy being sought after and in chaos, the teller’s voice is lost to the chaotic consequences of the experience (Frank, 2013). In quest, the storytellers want their voices to be heard as they want to share what sense has been made from the experience and use the experience as a tool for change.

The quest narrative was therefore underpinned by two themes: 1) *Making sense of having a child with cerebral palsy* and 2) *The want for social change*. By the first theme i.e. making sense of having a child with cerebral palsy, participants expressed the *auto-mythology* form of quest and by the second theme, participants enacted the *quest manifesto*. The theme *making sense of having a child with cerebral palsy* was also expressed in two-subthemes: *Cerebral palsy is the will of God* and *Cerebral palsy is a test from God*. The quest narrative, the underpinning themes and sub-themes are diagrammatically represented in figure 11.

Fig. 11: A diagram showing the quest narrative, themes and sub-themes



The next sections will present the two themes on the quest narrative and will demonstrate how both the quest auto-mythology and the quest manifesto forms were enacted by study participants by the use of these two themes. Though all the different family groups constructed the quest narrative, it was mostly dominated by parents and the extended family.

7.2 Making sense of having a child with cerebral palsy: the quest auto-mythology

7.2.1 Introduction to the theme

The expansion of illness experiences to reveal fate or destiny, the auto-mythology category of Frank's quest narrative typology, was demonstrated by all parents, extended family members and two siblings. This they did by attaching religious meanings to cerebral palsy, meanings that were beyond the physical level of human experience.

All Participants had affiliations with a formal or institutionalised religion and were active members of religious activities (going to church regularly) at the time of the interview and the meaning they constructed with regards to having a child with cerebral palsy appeared to be informed or influenced by these religious beliefs. The religious beliefs in this theme predominantly refer to the orally transmitted and lived religion that influenced the meanings attached to having a child with cerebral palsy. These religious beliefs were constructed by participants after both biomedical and alternative approaches to treatment had failed to provide a cure and they had acknowledged the reality of cerebral palsy with regards to its chronic nature. The findings of this study suggest that when participants could no longer imagine restitution, they constructed their experiences in a way in which the cerebral palsy condition was romanticised by describing it in an idealistic or unrealistic fashion; making it appear or seem better than it really is, and thereby enacting the quest *auto-mythology*. Therefore, in the quest auto-mythology stories that participants narrated, it appeared they used their religious beliefs and convictions to romanticise the experience of having children with cerebral palsy, giving it idealistic religious and romantic meanings like “Will of God” and “Test from God”. The sub-themes within this theme give descriptions of how the quest auto-mythology was enacted by study participants and will be presented in the next sections

7.2.2 Cerebral palsy is the will of God

Cerebral palsy is the will of God is a sub-theme that featured strongly in the narrative of most participants under the quest auto-mythology, where they attempted to make sense of the cerebral palsy experience. Some participants attempted to give an explanation to what the will of God for humanity means before attributing the will of God to the cause of cerebral palsy in the lives of the children. The general religious explanation held among participants with regards to the will of God appeared to be the concept of a God having a plan for humanity and ascribing events, whether favourable or unfavourable in the life of the individual, to God. Based on this, some study participants described a higher power that controlled whatever happened in their lives and stressed that nothing could happen without His permission. This notion is embedded in the statements below:

“Whatever happens in this life, happens by the will of God. No human does make anything happen”.... Duncan (father)

“God is the one who changes times and seasons and He is the giver of destinies and He knows best what is good for every individual”.....Samson (Grandfather)

From their belief in a higher power that controls everything in life, participants expressed the conviction of God’s reality and presence. They appeared to believe having a child with cerebral palsy was the will of God, but this was only arrived at once all avenues for cure had proved futile. This is typified by Natasha, the grandmother of Ivan, a 6 years old child with cerebral palsy. Attributing cerebral palsy to the will of God, she believes that it was the reason why her grandchild’s condition wasn’t cured despite all the help for cure they had explored. She highlights her past experience of having children herself, and her other grandchildren, none of whom have cerebral palsy. The exception is this child and therefore she ascribes it to “God’s will”.

“I think that God wanted the condition to be on the child, the reason the child was not cured. If it wasn’t God’s will that this condition should happen to the child, I believe it wouldn’t have happened. I have given birth to five children but did not see any of such conditions in my children. So, I believe that it is the will of God that has happened”...Natasha (Grandmother)

It appeared that Natasha’s reasoning permeated through most of these families as the members believed that for a child in their family to have cerebral palsy excluding all the other children, they believed that it was the will of God for that to happen and they appeared unable to identify another credible explanation.

“I know God gave me this child and He alone knows the reasons for giving me this child. All I know is that God gave me this child and He allowed this condition to come upon him”...Nancy (mother)

“It is the will of God that I get a child like this, that’s why He has given me this child. God has given me other children who do not have this condition and I appreciated God for this, and so if he has given me this one too, I must appreciate and accept it”.... Duncan (father)

Whiles describing the chaos narrative, participants mostly attributed the occurrence of cerebral palsy to mystery, demonic and supernatural happenings as they rationalised that the condition had not happened before in their family line but the focus changed

to the will of God within the quest narrative as they began to make sense of the condition and the fact that it couldn't be remedied despite the efforts they made in seeking remedy. Their belief in God's will was evident irrespective of their religious background. This was characterised by submission or surrender to the belief that God was omniscient and knew what was good for the child. Significant about participants' beliefs in God's will as the cause and effect of the child's condition, whether Christian, Muslim or traditionalist, was the concept of submission or surrender to God's will of a child with cerebral palsy.

"We have just left everything in the hands of God because it is He who knows why He gave us this child"....Leah (Sibling)

"You have to be patient with God and understand that He allowed this to happen to your child. Getting patient with God means you have left everything in the hands of God. I take it that it is God who created this child and has allowed this to happen to him so He knows what is best for this child. I also thought it wise that God knows the best for this child that is why this condition happened to him at the hospital. So you see, this is what I mean when I say I have left everything in the hands of God".....Norman (father)

"If it happens that my brother does not walk for the rest of his life, then it is the will of God that the child will not walk and we shall leave everything in God's hands because He knows why He gave this child to us".....Rita (Sibling)

Furthermore, participants tried to demonstrate that it was the will of God to give cerebral palsy to the children as their destinies. This notion was dominated by the extended family. By designating cerebral palsy as the children's destiny, participants appeared to believe that it was a condition that was bound to happen and there was no way of escape for the children, it was the purpose for which the children were created and cerebral palsy was a predetermined future for these children, by a higher power, God. For example, Peter, the grandfather of Ivan, a 6 years old child with cerebral palsy narrates that his grandchild's chronic condition is his destiny through God's will and such destinies cannot be altered, and thereby reinforcing or enacting the quest auto-mythology narrative.

“If it is God’s will that this child will walk, he will surely walk. However, if it is God’s will that the child continues to remain like this, he will continue to remain like this. If the child does not walk, then it means he was destined by God to remain like this till death. If God does not cure the child of this condition, then it means God has destined the child to live with this condition for the rest of his life. No one can challenge God to change His will or His plan” ...Peter (grandfather)

It also appeared that speaking about the child’s future brought an uncertainty consistent with the chaos narrative. However, they appeared to mitigate this uncertainty through the quest narrative by linking the child’s future to the will of God based on their trust in God. Trusting in the will of God for the child’s future was a belief expressed by most participants as they expressed uncertainties concerning the children’s future. Their expression in the will of God for the child’s future occurred at the point when they had made sense of the children’s condition and had attributed it to the will of God and it appeared they endeavoured to alleviate these uncertainties by believing that since it was the will of God for cerebral palsy to happen to the children, there is a sure future for them that only God knows about. To them, the reality of what the child could become in the future was dependent on the will of God for the child’s future. This finding is demonstrated by the extracts below:

“Ooh, I said I have attributed everything to God because it is He who gave us this child and he knows what He will use this child to do in the future that is why He has given us this child”.... Margaret (grandmother)

“Ooh, for her future, I don’t know anything about her future, only God knows”...Betty (Mother)

“Well, the child’s condition is in God’s hands. We may plan anything for the child but the Bible says that the ways of man are not the ways of God. It is only God who knows what this child would become in the future”.... Natasha (grandmother)

“If it is God’s will that he lives, he will live and become what God wants him to be. Since he is still alive and not dead till this time, I know his future is in God’s hands. I know God will open a way for him when he grows up. No one knows what he will be in the future. I know his future is in God’s hands

and by all means, God will make him a great person in the future”...Abraham

However, despite the expression of all participants in the will of God as the meaning attributed to having a child with cerebral palsy in the family, there existed some complexities demonstrated by the heterogeneous groups of participants. These complexities occurred when the various groups tried to provide a justification for why cerebral palsy would be God’s will. A finding shared by some fathers, mothers and extended family members but not siblings, that characterised some part of this complexity, was the conviction that the children were given as “gifts” through the will of God. For example, from the study sample, there were some participants including Florence (mother) and Arthur (father) who specifically wanted to have a male child. Florence had no boy child in her family and wished to have one. Arthur, who was a Muslim father, had a strong longing for a son; he reported that from his Muslim and northern traditions, only males could succeed their fathers so having no boy child in the family was of great concern to him. Based on their religious convictions, they reported praying to God to “gift” them with male children and when they finally had these male children, they saw them as gifts from God. Initially, they were happy following the birth of their male children but once they realised something was wrong followed by their children being diagnosed by cerebral palsy, they entered into chaos, especially when they knew more about the children’s condition with regards to its long-term nature. However, at the point of their experiences when they had come to terms with the condition and had made sense of cerebral palsy, they recalled how they had asked God to gift them with these children. They seemed to use their conviction that children are gifts from God, to serve as a justification for why God would will such children for them.

“I believe God gave this child to me as a gift because I asked God to give me a baby boy since I had no son. I asked God that if Sarah in the Bible asked for a child and He granted it, then He should grant me a baby boy. I asked and God indeed answered my prayers and has given me a baby boy. The Bible says every good and perfect gift comes from God. The Bible says that there are many purposes in the heart of man but only the counsel of God will prevail”...Florence (mother)

“I must accept it and appreciate it as a gift from God and He knows the reason why He gave it. I cannot say, “God, it is you who gave me this and this is bad so I can’t continue believing in you or can’t continue worshipping you” ...Arthur (father)

“It is God who gifts children to parents. And whatever child God may give to you as a parent, whether disabled or not, you must receive it in good pleasure”...Peter (grandfather)

Unique to the experiences of some mothers (n=2) in justifying cerebral palsy as the will of God was the belief that the children were given to them to strengthen the bond in their marriage. The first mother to have expressed this was Betty, a 37-year-old woman who had given birth to two children. The younger was 5 years 3 months old and had severe cerebral palsy and the older, who was in junior high school was 15 years old. Betty was cohabiting with the father of her two children who she says had promised to marry her after she had given birth. On giving birth, the child developed cerebral palsy and the marriage had still not taken place. However, it appeared from Betty’s statement that she perceived that having this child with CP had strengthened the bond between them. She was sure that even if there could be a likely divorce after they marry, the child could still bond the parents together as they would consider the child’s plight and disregard this divorce.

“So maybe God wanted this child to come first so that she will be a great bond between me and my husband before we officially get married and even if anything happens in future that may call for a divorce, we may consider the child and still stay together as husband and wife”....Betty (mother)

A second mother, Lydia, also expressed that cerebral palsy was God’s will to strengthen the bond in her marriage. Lydia is a 34-year-old mother with 4 children including a 10-year-old child with cerebral palsy. She is married and lives with her husband who is a pastor. However, Lydia disclosed that she was used to engaging in promiscuous activities unbeknown to her husband. She believes that God had wilfully given this child to her to make her stabilize the bond between her and her husband because with the dependent nature of this child, she could not go anywhere again and would, therefore, be “stable” with her man.

“Hahahaha, yea, at the initial stages of my marital life, I was a bit adventurous and promiscuous. God does not want me to roam haphazardly again that’s why he has given this child to me. So I believe that if I had given birth to a normal child, I would still be roaming or moving from one man to another. So God in a way wants to make me stable with this man that is why I believe he has given this child to me. With this child in my life, I cannot go anywhere again”...Lydia (mother)

From these mothers, it appeared it was their belief that God had willed a child with cerebral palsy on their families in order to ensure strong family ties and marriage stability. It appeared they saw strong family bond and marriage stability as what they have gained from having a child with cerebral palsy, reinforcing the quest narrative that something is to be gained from the illness experience (Frank, 2013).

Furthermore, there was another unique construct by the extended family with regards to cerebral palsy as the will of God. This they expressed that cerebral palsy was the will of God as punishment for the parents’ sinful deeds.

“We believe that it might be the parents’ fault that has resulted in this. It could be the fault of the father or mother that this condition had happened”....Portia (Aunt)

To provide a justification for the belief that cerebral palsy was the will of God as punishment for the sin of the parents, the extended family members would refer to stories in the Bible where some persons with disability were taken to be a result of their parents' sins, to support this claim. This is typified by Emelia’s statement

“In the Bible, I remember there was a blind man who people inquired from Jesus to find out the cause of his illness, whether it was as the result of his mother’s or father’s sin. We think it could be as a result of what her mother or father had done”...Emelia

The extended family demonstrated this belief of cerebral palsy being the result of the parents’ sins to the extent that even in one family, the grandparents and the Aunt to the child with cerebral palsy had a meeting with the mother of the child to find out the specific sins she might have committed in the past that had resulted in her child having cerebral palsy.

“You know the child’s mother is from the north of this country and these people from the north are noted for spiritualism and witchcraft. So, when the condition happened, we inquired from the mother whether she had disappointed somebody and did not marry him and as a result, the disappointed man, in wanting to punish the mother had cast this condition on her child. The mother however, replied that she had done no such thing but we still do not believe what she told us”...Portia (Aunt)

In another family, the belief that cerebral palsy was the will of God as a result of the parents’ sin, mostly propagated by the extended family, appeared to have affected one father, Kennedy. Kennedy doubles as both a graduate teacher and a junior pastor in his church. With cerebral palsy being understood by the extended family as the sins of the parents it appeared that this notion propagated by the extended family had affected Kennedy to an extent that he had begun making religious prayer rituals to always ask God for the forgiveness of sins that he might have committed unknowingly and remedy his child’s condition. This father appears to have accepted that cerebral palsy was God’s will as punishment for his sins and his quote suggests that if only God could forgive him of his sins, his child’s condition could be healed.

“I cry deeply and seriously, pray and ask God that if it was something that I had done wrong that has brought this condition on the child, He should forgive me and heal this innocent child”Kennedy (Father)

7.2.3 Cerebral palsy is a test from God

Cerebral palsy is a test from God, is another religious perspective that reinforces the auto-mythology form of quest constructed by study participants. It is another perspective of quest that participants used to romanticise the cerebral palsy condition, making it appear better or making it an ideal situation. However, this theme was the construct of the parents of children with cerebral palsy and reinforcement by the opinions of others and neither the extended family nor siblings constructed this narrative. Furthermore, this perspective of quest was dominated by fathers compared to a small number of mothers who identified with this theme. All fathers believed that the condition of their children was a test of faith from God

“For my child, I strongly believe that it is God who gave this condition to my child just to test my faith in Him”....Abraham (Father)

Providing an explanation as to why God would test them this way, the parents expressed that the test of cerebral palsy was proffered on them by God to ascertain whether or not their faith in God would waver in times of trouble and adversities.

“I believe that God is testing me with this child whether I would still continue believing in Him”...Lydia (Mother)

“If anything bad happens to you as a worshipper of God, then it is God who is testing your faith. So I take my son’s condition as a test from God. Whoever that will profess a belief in God, God will put you to a test to find out whether you would still believe in Him or renounce your faith in Him. God would want people around you to see whether you are a true believer in Him so He will put you to a test”....Arthur (Father)

The quotes above signify that these parents believed their children’s condition was a deliberate action or procedure that God was using to test the quality, the reliability and the strength of their religious faith. Arthur’s statement suggests that an unflinching or unfaltering faith in God or not “renouncing” his faith in God, would mean that he is a strong believer and his faith would be credible before God, a meaning that reinforces the quest plotline of romanticism. This finding could also offer a possible explanation to a later question pertaining to their faith in God. When fathers were asked what would happen to their faith should their children’s condition remain the same, they all affirmed that they would continue trusting and having faith in God:

Interviewer:

So what will happen to your faith in God if He does not heal your child?

Duncan:

Nothing will happen to my faith. My faith in God will never change. Nothing will be able to separate us from God whether our child walks or not. So nothing will happen to my faith if the child does not walk

Among the Christian fathers, the belief that cerebral palsy was a test from God was also co-constructed by their encounter with some versions of the Bible where Biblical characters described as “men of God”, experienced adverse life situations and conditions. These versions of the Bible were therefore quoted as a justification to support their belief that cerebral palsy was indeed a test from God.

“The biblical Job was put through a very severe test by God but at the end, he became victorious. He suffered the severest of sicknesses with sores all over his body but when God’s time was due to heal Job He healed him and his skin even looked like that of a baby, very fresh and soft. I take my child’s condition as a test from God, like the biblical Job, who went through tests and trials from God”....Duncan

It is of significance, to note that Duncan, could well relate with this biblical reference quoted above because he himself was a pastor (man of God) and therefore aligned his experience of having a child with cerebral palsy with that of Job in the Bible. He seemed to be convinced that as God tested Job’s faith with a severe condition, his faith was also being tested with the severe condition of his child. According to Frank who developed his narrative typologies from his experience as an individual with a chronic condition and from that of Job in the Bible, attributing or aligning one’s experiences to that of Job, means that the person understands the experience as a puzzle which still needs a solution (Frank, 2013). It then appears that within the quest stories, restitution still lurked at the background in which participants are still waiting for an eventual solution to the cerebral palsy condition of their children. This was made evident in the restitution sub-theme “transcendent hope for cure” which has been discussed in the restitution chapter (see chapter 5, section 5.3.3.2). This is also a proof to the fact that even with quest, restitution never went away as it continued to linger as the secondary narrative.

Apart from the fathers and some mothers believing that their children’s condition was a test from God, there was also a dominance of religious beliefs from others' perspectives (neighbours and friends) to cerebral palsy being a test from God as demonstrated by the below extract. It appeared that from others' opinions, they seem to have constructed that cerebral palsy was a difficult test that must be endured patiently.

“The people in this house always console me by telling me that, “your child’s condition is a very difficult one but let’s pray about it and leave it in the hands of God, and we also pray to God to grant you a heart of patience”...Arthur

It would then appear that deep-rooted in society, is the notion that cerebral palsy could be both the will of God and a test from God and this could have also informed the narratives that participants constructed.

7.3 The want for societal change: the quest manifesto

The quest manifesto is the least gentle type of quest stories because it always carries with it demands for social action (Frank, 2013). The quest manifesto was enacted by participants when in their stories of having lived with children with cerebral palsy, they called for social change. Such social changes focused on the rights of children with cerebral palsy and their families, cerebral palsy awareness, change in societal attitudes towards cerebral palsy children and their families, equalisation of societal opportunities, change in government policies and government interventions for these family members. They also demonstrated a sense of taking back the control they had already lost, a finding which is consistent with the quest narrative. For the study participants, it appeared that their main impetus for wanting societal change was influenced by what they had observed and learnt through the mass media, regarding how persons with disability in the western world are treated and accorded their rights. They felt that western societies and their governments have done much for persons with disabilities but the same cannot be said about the Ghanaian society. They felt that if the western system of disability inclusion could be replicated in the Ghanaian society, the children would fare well and would have the future lives they desired for them. They, therefore, urged society and the government to consider this. Samson’s statement below typifies this finding.

“Oh, yea. We all watch the television, we visit the internet and go to other social media sites like Facebook and we see persons with disabilities in America, Europe and other western countries. I once watched a man on television who had a disability, but this person was a medical doctor. Some are lawyers. I have seen most of these people on the net who are doing something good despite their disability. These people in the western

countries have blood running through their veins just like us but they have been able to help the unfortunate ones having disability living among them. Why can't we do the same thing for the people having disability in our own country? I am therefore pleading with the new government to remember and plan for the persons with disability in our country, for there is an adage that says that "the only useless person is the one who is dead. The government should, therefore, help our children and friends having this condition so they too can have a better life".... Samson (Grandfather)

"Yea, my wife attended a programme in London, and she happened to be in one of the schools that take care of children with disabilities. She came to tell me how well these children are looked after and the support and attention they get. If we could have such support and attention for our child, we would love it but where to get that support in Ghana here and the money to even pay for that support services is the problem"... Kennedy (father)

The quest manifesto narrative with regards to change in attitudes was common among all the groups of participants. Under the quest manifesto, it appeared participants felt that disability is a social issue and that society could do more to help family members and these children. Therefore, participants cited societal behaviours and attitudes that people showed towards them and their children and they appeared to use the quest manifesto as a tool to call for eradication or a change in such attitudes and behaviours. Study participants felt that society excluded and looked down on the rights of children with cerebral palsy. They felt that authorities could help to enforce the rights of their children

"Most of the time, people look down on such children and their rights are often abused. So people in high positions could make sure that those who abuse the rights of these children are brought to book or punished appropriately"...Fanny (Sister)

Relating to attitudinal barriers, participants narrated that the children are not treated well by society. They described how society had been negative toward children with cerebral palsy, branding them "useless" and participants appeared to challenge such stereotypical views of their children.

“In this country people treat these children like trash, people don’t respect them, and they think they are useless, but these people are normal people like anybody. Having this condition does not mean their brains are damaged or not functioning. Their brains are alright”...Nelson (father)

All participants felt that the children were the subject of societal rejection, seclusion, and ridicule and described how often they encountered people within their communities who ridiculed their children and sometimes took advantage of their disability to maltreat or bully them especially in the absence of parents. Abraham’s quote typifies the maltreatment that society sometimes metes out to these children with cerebral palsy.

“What I have discovered in this town is that at the times when I am not around or have travelled out of this town, some of the people who may see the child gives him some alcohol to drink. I suspect it is the boys in this town that does that. They lure him to drink alcohol and he would get drunk heavily. There was one time I returned from the farm to find him heavily drunk and he almost died had it not been the fact that his other siblings found him and brought him to me. I was in the farm when one of the children ran to tell me that somebody has given him alcohol and he is heavily drunk and may even die. I ran as fast as I could and came to the house, prepared some mashed kenkey for him to drink before he got a bit well. So I made those who work at the information centre here to announce to the whole community that if it happens again that anybody gives my child alcohol and I find out who did that, I would let the police arrest such an individual. Many people in this town know the child because of his condition so whenever someone does anything bad to him, somebody would run to me and report”...Abraham (father)

Study participants were therefore positive that such attitudes and behaviours expressed towards their children could change if society was educated more and made aware of children with cerebral palsy and especially about the nature of their condition. They felt that the stigma towards their families and the children would wane if the public had more knowledge about cerebral palsy. They charged the government

and other stakeholders to take on the endeavour of educating the masses about disability to effect the desired change in attitudes towards children with cerebral palsy

“The government could help and organise awareness campaigns for all Ghanaians to know that these children are humans and not animals as some people say”...Abraham (father)

“I believe that the government can also task the mass media to engage in educating the masses about conditions like this in order for people to be informed that these children are humans but not animals. The mass media can bring out many educative documentaries to educate the public about these children so that the perceptions of people about these children will change”...Portia (grandmother)

“Hmm, it is not easy but I am thinking that if the government steps in to do mass campaigns about children with cerebral palsy, many people would become aware of these children and it will be easier for these children and their families to be accepted in the vicinities in which they live. Or on the other hand, all the parents or family members of these children can come together, form a group that will educate the public on the various mass media about this cerebral palsy condition”...Betty (mother)

The quest manifesto was furthermore enacted by participants when they suggested that institutional barriers could be removed to ensure that the children may redeem the societal opportunities that they felt they were losing. This perspective was common among the parents of these children. Parents called specifically for changes to the educational and health systems and expressed a need for social intervention services which are currently absent for persons with disability in the Ghanaian society. Throughout the quest manifesto narrative, it was common among parents and siblings to express their concerns about the unsupportive educational systems in Ghana which they felt were not able to cater for the educational needs of their children. They urged the government to have a review of the education system and factor into it the inclusion of children with cerebral palsy.

“Concerning the schools too [mainstream schools], there are very scanty schools that take care of these children and even most of these few ones are individually owned so they are very expensive. If the government can

help us in this direction, it will go a long way to help families living with children with cerebral palsy. The government should pay attention to creating more schools that can admit these children”...Harriet (mother)

“And you know children like this are not accepted into the mainstream government schools so if the government can build special schools for these children, we would be very grateful. Yea, so we need loads of help from the government. If we have more special schools like the mainstream schools, they would be very helpful for these children”...Rita (sister)

“I will tell people in position, that they should help the children living with this condition. I saw a similar child like this on Television. This child was 8 years and no school was willing to admit him because of his condition. So, if there is any opportunity, they should please help the children who have this condition”.....Fanny (Sister)

In schools where they accepted such children, parents felt that attitudes of some teachers were not desired as they reported that many mainstream schools expressed reluctance in admitting children with cerebral palsy especially when they have not improved in mobility and speech. The parents felt that the changes could be made to these barriers that prevent their children from accessing educational opportunities. Kennedy's quote from his experience typifies this finding

“Yea it is true but children with disabilities who are allowed into the mainstream government institutions to receive special education are those who can talk. So if the child cannot walk nor talk, they won't grant her an admission, unless you send her to a private school that gives special education and these are extremely very scarce in the country. Those children who are also received into the mainstream government institutions are quite independent and can do most of their activities of daily living. There is no mainstream school that would receive a child like this who cannot walk nor talk and cannot do anything for herself. No teacher in the mainstream school would get time for the child to give her personal care if she defecates or urinates on herself.... Kennedy” (father)

Parents enacted the quest manifesto narrative when they felt that changes to the healthcare environment would also be beneficial to them as well as their children. Specifically, mothers expressed the need for some sort of respite care. They expressed the need for established care services in society to which they can turn to and have the confidence that their children would be well looked after while they concentrated on economic endeavours. Mothers, therefore, called for such care centres to be constructed by the government for children with cerebral palsy and other children with disabilities.

“I wish there is some kind of special care homes or hospitals for these children where they would be admitted to receive daily treatment and daily personal care. In that case, the parents would have been free to focus on their jobs and to raise money to care for the child. So, I wish for a place where these children can be admitted and cared for, whether walking or not so that we the family members can be free, work for money and support these children properly. A place where this child can be supported so, even if he cannot stand, he can sit and eat on his own. If all these children in different families can be admitted to such places for some period of time, the parents and other family members would also be free to focus on other things. If the government can see to it that such special care homes are built in the country, it would be beneficial for us”.....Nancy (mother)

Most extended family members, however, expressed a different view on respite care suggesting that the government could adopt these children outright from their parents through some social intervention programmes. They felt that in this way, the burden on family members as a result of having children with cerebral palsy would be reduced drastically

“I would love that the government or a government department would come in and adopt the child and raise him. If the government is able to raise something like children’s home for these children where they are kept and nurtured, we the family members would also have time to do other things. We would have loved it that way. It would also have reduced the burden we have to go bear in caring for this child”...Peter (Grandfather)

Some mothers furthermore enacted the quest manifesto as they described their experiences with national healthcare facilities and government healthcare practitioners. Mothers felt that healthcare facilities could be improved, more facilities erected, and more professionals employed by the government to cater for the needs of the children with cerebral palsy. They felt that the pressure on the small number of existing facilities would be eased when more facilities are built and more professionals employed. It appeared these mothers felt that if this is done, competing for the attention of health professionals, would be reduced when they go for physiotherapy management for their children and their children would be properly cared for.

“we need a lot of support because we go to the physiotherapy once a week and some of the doctors have even said that going for physio just once a week is not enough but you can’t also blame the physiotherapist because the children with cerebral palsy are very many and it is not in every hospital that you can get a physiotherapy unit. Many of the hospitals and clinics don’t have physiotherapy units and there is too much pressure at the [name of hospital]. When you go for physiotherapy, you end up spending the whole day at the hospital because of the pressure there. If all hospitals were having physiotherapy units it would help ease up the pressure at the regional hospitals. Sometimes when it gets to the turn of your child, the therapists are already tired, so they don’t do enough for the child”...Harriet (mother)

Most Parents further enacted the quest manifesto as they felt that social welfare intervention service, in terms of receiving monetary benefits for themselves and their children would help ease the burdens associated with financial problems they encounter every day in their lives. They felt the need to make their financial difficulties visible to government policymakers in order to acquire financial aid or monetary benefits. All the different groups of participants seemed to suggest that helping families, and especially parents of children with CP demanded policies that are more responsive to the financial needs of parents. It appeared they knew about how foreign governments in developed countries have put in place benefit packages for children with disabilities and their family members. They felt that such same policy regarding benefit for children with cerebral palsy and their families, would help alleviate the financial hardships they go through as a result of having children with cerebral palsy.

“There should also be a government policy concerning these children. I read a document online about one country, it’s either Australia or Netherlands, it was written in the document that if a parent has a child with disability, the family of the child receives some aids from the government, so at least if such policies are also established in Ghana, it will help because most of the parents of these children have stopped working or lost their jobs because of these children. Even if the government could take the medical bills and school fees that parents pay, it would ease the burden. The government should at least do something to support”.....Harriet (mother)

77.4 Reflexivity: data analysis and interpretation

Data analysis was the most challenging part of this research. The transitioning from thematic analysis to narrative analysis took not less than 3 weeks as I stepped back to read and reflect on the findings that had emerged from thematic analysis to consider potential explanatory frameworks that could serve as an anchor to bring an in-depth explanation to the study findings. It seemed I had reached an analytical deadlock at this stage. Section 3.8.9.2 has already described how I came across Frank’s narratives. Before I could use Frank’s narratives, I had to read Frank’s book, *the wounded storyteller* (Frank, 1995), from cover to cover, and get an in-depth understanding of the three narrative types. Reflecting on my findings, I discovered that my findings lent themselves flexibly into Frank’s typologies. The findings from analysis therefore, were not forced to fit Frank’s perspectives but rather they did so naturally and without overlaps. The inductive approach to data analysis before narrative analysis was applied to themes, made me minimise my own influence on the study results. The use of inductive coding prevented the imposition of Frank’s narratives on data as I was able to derive concepts inductively. The inductive coding approach and the identification of emerging concepts particularly helped in making interpretations and conclusions that emanated from participant stories. A reflexive position was also kept during data analysis and interpretation of results through acknowledging my roles in these processes. I made reflections on how my knowledge, professional background and experience could influence meanings drawn out of the data.

7.5 Conclusion

This chapter has demonstrated the construction of the quest narrative by study participants from their experiences of living with children having cerebral palsy. It has also demonstrated how participants mainly used the two forms of quest, auto-mythology and manifesto to construct their experiences of living with children with cerebral palsy and in making meaning of the cerebral palsy condition. This chapter has furthermore demonstrated that the construction of the quest auto-mythology was underpinned by religious beliefs where participants expressed that cerebral palsy was the will of God and a test from God. The quest manifesto was also underpinned by the desire of participants for change in societal systems and attitudes as they seem to report that society further adds to the disability of their children and called for a change to occur. However, unlike the chaos and restitution where more sibling views were involved, it appears half of the sibling group did not construct the quest narrative at all. The quest narrative, therefore, presented a dominance of parents and extended family views.

CHAPTER EIGHT: CRITICAL SYNTHESIS OF STUDY FINDINGS

8.1 Introduction

The three results chapters on Restitution, Chaos and Quest, have demonstrated how these narratives were constructed and demonstrated by participants at different time points in their experiences. Restitution was mainly underpinned by the health-seeking behaviour of study participants as they explored avenues to find a “cure” for the children with cerebral palsy. It was also evident that chaos became the dominant narrative as participants perceived that both biomedical and alternative care had proved futile and participants felt they could do no more about the children’s condition. Also, at this point, there was an intransitive and transcendental hope for cure. It has also emerged that societal and cultural opinions about cerebral palsy and the personal impact of cerebral palsy on the lives of participants, also affected the enactment of the chaos narrative. Furthermore, it has also been demonstrated that the quest narrative typology became a strong feature in the experiences of participants when it appeared they were coming to terms with the condition and had made sense of it.

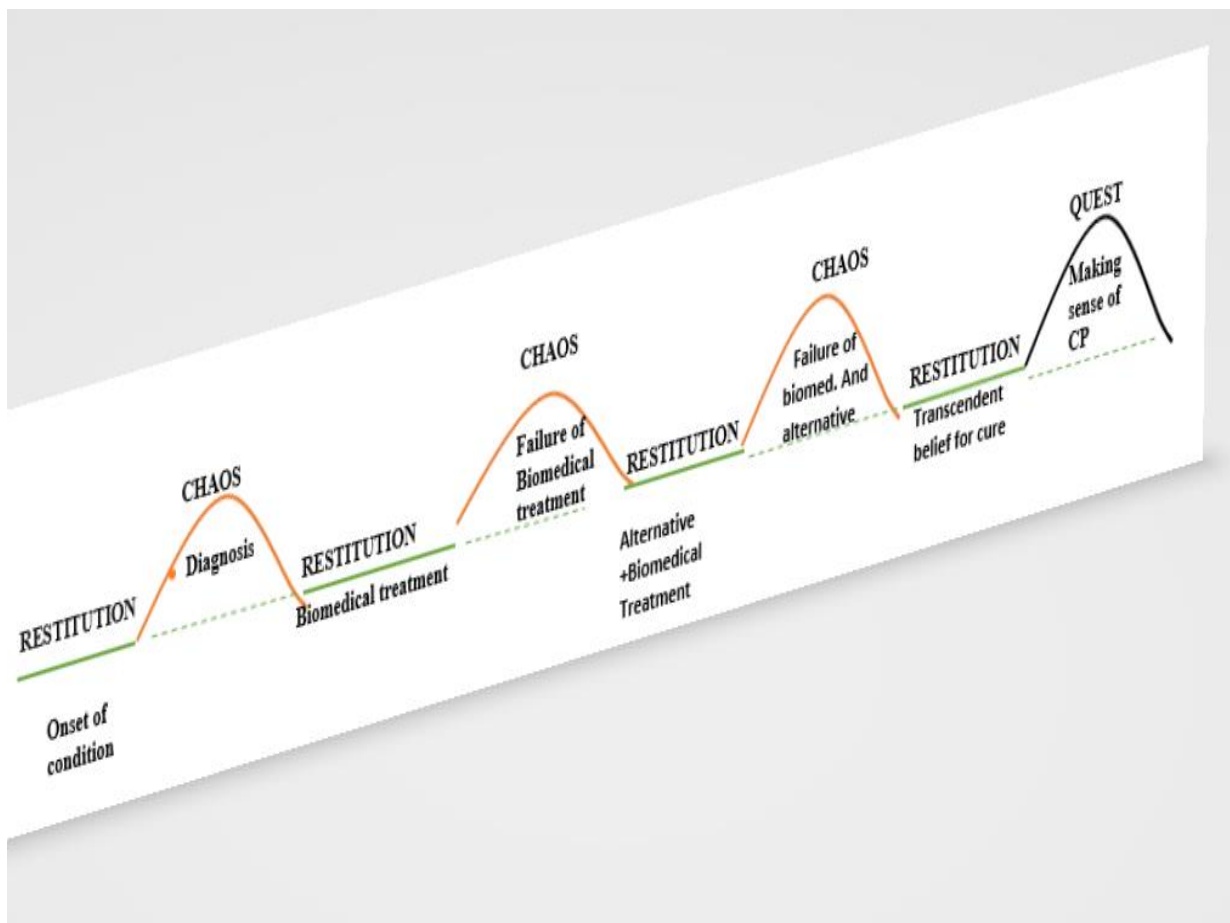
One of the objectives of the study was to explore potential differences between the views of different participant groups. However, the study findings have demonstrated that all groups of participants shared similar experiences and no major differences in narratives were observed. It is possible that as study participants had mostly dwelt together for a long time, their experiences of living with a child with cerebral palsy could have been shared and this might have influenced how participants constructed their narratives and created the similarities shared within each narrative type. Furthermore, at this initial stages in the lives of these children who are totally dependent on their family members for survival, their family members are functioning in the stead of these children and the illness stories that are supposed to be told by these ill children themselves, are being rather told by their family members. Would the narratives of these family members change as the children mature into adulthood, own their stories, and their dependence on the family members increase? That notwithstanding, there were some nuances and complexities in how the narratives of restitution, chaos and quest were constructed by participants which are manifested in narrative dominance, movement and timelines. This chapter will, therefore, triangulate the findings of this study and also pull together these complexities and nuances within

each narrative type. The chapter will utilise the metaphor of the kaleidoscope proposed by Frank (1995, 2013) to underpin the movement of the narrative typologies.

8.2 The kaleidoscope effect of narrative movements, narrative dominance and narrative timelines in this study

This chapter likens the narrative typologies of Frank enacted in this study by participants, to the operation of a kaleidoscope to further enhance the interpretation of the narrative movements in this study (Frank, 1995). In turning a kaleidoscope, one particular colour of glass may be prominent in one view and recede to the background with another turn, only to appear in a new configuration with the next shift of pieces. This chapter will compare the narrative movements within this study to the turning of a kaleidoscope and will establish that the narratives constructed by study participants overlapped and interplayed with one another. To clarify this, there were points in participant narratives in which some narratives dominated the others or became the primary narrative while the others became secondary narratives. Figure 12 depicts the kaleidoscopic movements of the narratives constructed by study participants. Each of the narrative types of Frank was expressed by participants at different points within their interviews and there was no single interview that had a perfect “fit” with only one narrative typology. Furthermore, in comparison with the different colours in a kaleidoscope, each of the narrative turns occurred in different timelines, for the different participant groups. This occurrence demonstrated Frank’s view concerning his narrative types as he theorised that the typologies do not capture people’s stories and constrain them within one narrative type but rather are useful in the identification of the direction of the narrative and thereby acting as supportive listening tools to better understand the experiences of people (Frank, 1998). Participants presented the events in their narratives chronologically, commencing from the pre-diagnosis period and their narratives progressed and occurred at different points and timelines through to the time of data collection. The narratives captured from data were deeply grounded in their experiences as a result of living with children having cerebral Palsy.

Fig. 12: Narrative turns and movement



¹The figure above is a diagrammatic representation of how the narrative movements occurred in the current study. The green line represents the restitution narrative, the broken green line represents restitution as a background narrative, the orange line represents the chaos narrative and finally, the black line shows the quest narrative. This diagram, therefore, would demonstrate that at the onset of CP, all participants began their stories with restitution. However, at the point of diagnosis restitution became the background or secondary narrative, as chaos became the primary. The commencement of biomedical treatment witnessed another narrative turn from chaos to restitution. However, restitution became the background narrative again as there was another turn to chaos when participants perceived biomedical treatment had failed to provide cure. Another narrative turn from chaos to restitution occurred when participants combined alternative treatment with biomedical treatment. When both biomedical and alternative treatment failed, chaos dominated again as restitution became the background narrative. However, their desire for cure never went away but rather at this point, they looked forward to restitution in transcendence. Finally, the quest narrative emerged as participants appeared to have made sense of CP

8.3 Restitution

This section will highlight that although restitution was a consistent narrative, it moved in turns between being the primary and a secondary narrative. The results chapters have demonstrated that all participants commenced their narratives with the restitution narrative typology. Metaphorically, restitution was the first “colour” (narrative typology) to show in the kaleidoscope of the narratives of participants. As has already been demonstrated in the findings, the restitution narrative began when participants suspected that “something could be wrong” with the children and endeavoured to seek an explanation and possible solutions for what they suspected might be wrong. However, there were complexities and nuances in how participants constructed restitution, restitution dominance and the timelines in which restitution commenced or occurred for participants (i.e. Parents, extended family, siblings). With regards to restitution dominance, parents dominated the restitution stories, followed by participants from the extended family. Siblings demonstrated the least construction of the restitution narrative.

For all participants, the enactment of the restitution narrative commenced when decisions were taken to find out what could be wrong with the children through help-seeking. By this action, participants demonstrated the restitution plotline that “to every illness, there is an equal remedy”. However, there were differences in how restitution was constructed at the point of suspecting “something might be wrong” with the children. While parents mostly engaged restitution actively at this point, it appeared siblings and extended family members engaged restitution passively. Parents constructed active restitution because they took the child to access biomedical help and mostly paid for the costs involved in seeking such help. Parent’s restitution narrative during this period involved pragmatic actions taken to find out what was wrong with the children. It was within this time period that parents sought help and explanations aligned with the biomedical model of healthcare. They engaged health professionals for medical examinations, diagnosis, treatment and prognosis. Siblings and extended family members constructed passive restitution narratives; they were not directly involved in help-seeking at this initial stage but rather demonstrated a belief that biomedical help could bring about the realisation of restitution for the children.

Both passive and active restitution narratives moved linearly and chronologically from

the pre-diagnosis period when it was perceived that “something was wrong” to the time of diagnosis as most family members were expecting that the condition of the children could be rectified through biomedical consultations. However, following diagnosis, participants became aware of the long-term nature of cerebral palsy which resulted in a narrative turn from restitution to chaos. With chaos assuming the foreground, restitution became the secondary narrative at the time of diagnosis and the period immediately following it. The start of the biomedical management of cerebral palsy brought another narrative turn, this time from chaos to restitution. At this point, there was a change from passive restitution to active restitution for both siblings and extended family members as they all became actively involved with parents in seeking a “cure” for the children. Many siblings and extended family members also became involved in accessing biomedical help and took part in helping with prescribed biomedical exercises at home for the children. Narratives of all participants from this point were embedded in active restitution as they participated actively in seeking a cure initially within the confines of biomedical healthcare and later through the combination of alternative treatments and biomedical treatment as they perceived biomedical treatment alone was failing to provide restitution. At this point, all participants in the different heterogeneous groups demonstrated a similar belief in alternative treatment by attributing some improvement they had observed in the children to this.

As participants came to the realisation that both biomedical and alternative help had failed in fulfilling restitution, they demonstrated another narrative turn from restitution to chaos. At this point, restitution became the secondary narrative while chaos assumed the primary position as mostly, participants felt they were losing control of the children’s condition. Participants’ longing for a cure never went away but demonstrated their hope for cure both intransitively and transcendently. Through Intransitive hope for cure, which was the construct of siblings and mothers only, they believed that the children would eventually get well as they matured into adulthood. All participants from the heterogeneous groups, also demonstrated a belief in transcendence, hoping that a higher power or a supreme being (God) would bring a cure miraculously to the children. At this point, there was a change in emphasis from a “treatment” (alternative or conventional) to a belief in God for cure. This belief in transcendence was demonstrated by all participant groups.

8.4 Chaos

The findings chapters have demonstrated that the chaos narrative constructed by participants were mostly underpinned by a loss of control expressed through stigmatisation, cultural beliefs and the personal impact of living with a child with cerebral palsy. As demonstrated in the findings, chaos stories occurred intermittently and interrupted the restitution narrative. There was a narrative turn from restitution to chaos during the period of diagnosis and the period immediately following diagnosis. However, like restitution, some complexities and nuances occurred in the chaos narrative for participant groups with regards to dominance, timelines and personal impacts of living with a child with cerebral palsy.

Like restitution, parents dominated the chaos narrative as they appeared to share more chaos stories than any other participant group. With regards to narrative timelines, parents were again the first among the heterogeneous group of participants to construct the chaos narrative. For the parents in this study, the construction of the chaos narrative initially occurred both at the period of diagnosis and the period immediately following diagnosis, when they were engaged in active help-seeking to find out what could be wrong with the children and to also find a possible remedy. Parents first constructed the chaos narrative as they gained diagnosis for their children. At this period, the chaos narrative constructed by parents was underpinned by confusion, disturbance and uncertainty when they knew about the long-term nature of the condition.

Whereas chaos initially occurred for parents at the time of diagnosis and traversed to the period immediately following diagnosis, it appeared chaos had a simultaneous occurrence for both siblings and extended family members and this happened during the period immediately following diagnosis; this was the period when the news about the nature of cerebral palsy reached most siblings and most extended family members. Hence there were differences in the timelines at which parents and the two other heterogeneous groups (siblings and extended family) constructed chaos. Even though differences existed in the timelines at which the parents and the rest of the heterogeneous groups initially enacted chaos stories, there were no differences in the chaos stories constructed by all the groups at this point as their stories appeared to exhibit similar underpinnings of confusion and emotional disturbances.

The chaos narrative enacted during diagnosis and the period immediately following it was short-lived as it appeared that members gained a hope of restitution when the children began receiving biomedical management of the condition, mainly through physiotherapy visits to the hospital. Chaos again dominated participant narratives and became the primary narrative typology for participants as they realised that biomedical approach was failing to provide the hoped-for outcome. At this point however, there were differences observed between the chaos stories told by parents and those told by siblings and extended family members. For parents, the chaos stories at this point were dominated by chaotic emotional experiences which caused a profound sense of loss of control as they began to realise the long-term nature of cerebral palsy. For both siblings and extended family, it was witnessing the loss of emotional control from the parents of these children, which in turn brought about a loss of emotional control in themselves. Despite this difference, there were some similarities among participant stories at this point which is evidenced by all the different participant groups perceiving that medical negligence on the part of health professionals could be a potential cause of cerebral palsy. This perception led to a further enactment of the chaos narrative by study participants.

With the addition of alternative treatment to biomedical treatment, chaos became the secondary narrative and restitution assumed dominance again. This narrative turn from chaos to restitution occurred because participants believed that alternative treatment could complement biomedical treatment to fulfil their desire for restitution for the children. Failure of both biomedical and alternative treatment created feelings of loss of control of the children's condition as parents, siblings and extended family members felt that there was nothing that could be done about cerebral palsy again.

With failure of biomedical and alternative treatment, there was the evidence of a dominance of the chaos narrative underpinned by cultural beliefs demonstrated in the talk of most participants compounded by others' opinions that depicted cerebral palsy to be mysterious, supernatural and demonic, a characteristic of the chaos narrative shared by parents, siblings, and extended family. However, data analysis made it evident that even though such cultural beliefs about cerebral palsy with the underpinning mystery, spiritualism and supernaturalism, were observed in the chaos narratives from the different participant groups, they were dominant in the views of the extended family members in comparison with the other participant groups.

From the narratives of all participants, the chaos story appeared to occur in some sequential order from the point of diagnosis to the point where it was realised that both biomedical and alternative approaches have failed to provide cure. However, the progression of the chaos story from this point onwards appeared in no sequential order and therefore became an anti-narrative, a characteristic of the chaos typology of Frank (Frank, 2013). From the anti-narrative chaos stories, it was consistent among participants that living with a child with cerebral palsy resulted in job problems, financial hardships, anxiety about the condition which had become chronic and inability to fulfil family responsibilities. Telling of chaos stories at this point, therefore, was focused on the personal impact of cerebral palsy.

Constructing the personal impact of cerebral palsy on their lives, most participants narrated a loss of opportunities due to the dependent nature of the children with cerebral palsy. Participants reported on the loss of opportunities in fulfilling their future dreams and aspirations. While there were no observable distinctions in the different heterogeneous groups with regards to what “lost opportunities” meant for them, it was evident that this finding was dominant among parents as they reported more issues concerning the loss of opportunities than all the other participant groups. Similarly, the experience of financial burdens as a result of living and caring for a child with cerebral palsy, which contributed to further enactment of the chaos narrative, was common to all participants although this was greatest among the parent group in this study. That notwithstanding, there were some observable differences in how each participant group in this interview experienced financial burdens due to living with children having cerebral palsy.

Almost all mothers interviewed in this study (9 out of 10) had stopped engaging in their income-generating activities to care for the child with cerebral palsy and therefore could no longer contribute financially to the daily living expenses of the family. This had a significant impact on fathers as they had to shoulder the financial side of family responsibilities as sole breadwinners of the family. These fathers reported difficulty in meeting the daily needs of their nuclear family and consulted friends and financial firms for loans. Within some nuclear families, the consequences of financial burdens faced by parents and the difficulties encountered by fathers in providing for their spouse and

children, threatened a potential family breakdown, a characteristic of the chaos narrative. Siblings, interviewed in this study, especially those who were in school during the time of the study, experienced the repercussion of the financial burdens reported by parents as they reported a loss of control over their learning and education due to their parents' inability to cater for their schooling and other domestic things they needed. The extended family members also contributed to the chaos narrative based on financial hardships faced by parents as they felt that they had no control over helping these parents come out of such financial situations.

8.5 Quest

The quest narrative typology became a strong feature in the experiences of most family members when it appeared they were coming to terms with the condition and had made sense of it. This did not happen at the exclusion of the other two narratives of restitution and chaos. As it is described in the restitution and chaos chapters, the desire of participants for restitution to occur never went away but as the dominant plotlines became demonization of illness, social stigma, personal impact of cerebral palsy and coming to terms with the condition or making sense of the condition, the restitution narrative for many of the participants was absorbed into the background while chaos and quest emerged in the foreground. The quest stories told by family members having children with cerebral palsy occurred within the auto-mythology and manifesto forms of the quest narrative typology. From the study findings, it became evident that participants used the auto-mythology and the manifesto and not the memoir. They used the manifesto form of quest when in their experiences they called for social change and suggested society should do more to support children with cerebral palsy and their families. In this, they appeared to have met cerebral palsy "head on", using it to their advantage and as a motivator to press on for social change, a finding which is consistent with the quest narrative plotline. The auto-mythology form of quest was demonstrated when in their stories they attached religious meanings to their children having cerebral palsy and thereby linking CP to "the will of God", and a "Test from God". In this way, they romanticised what cerebral palsy meant for them, linking cerebral palsy to fate and destiny (i.e. if CP was the will and test from God, then it was meant to happen and could not be altered).

From the data analysis, the quest narrative turn became evident from participant interviews when it appeared participants had come to terms with cerebral palsy and were making sense of the condition but the timeline with regards to the different heterogeneous groups was not clear cut. It was therefore not clear from data analysis when each participant group joined the quest narrative but there appeared to be a general timeline, i.e. when they made sense and came to terms with the condition. Realising the long-term nature of cerebral palsy, the religious beliefs of participants influenced their perception of having a child with cerebral palsy in the family. Participants told quest stories in which it appeared they had come to terms with and had made sense of why cerebral palsy had happened to their children and constructed a “new insight” (Frank, 2013) to the cause of cerebral palsy. It appeared that through this new insight, they had accepted the change (i.e. cerebral palsy) that had happened in the children’s bodies and made attempt to find meaning into this change and in their attempt to find meaning it appeared they evaluated (quest is also characterised by evaluation) the condition of the children, expanding the condition as fate or destiny of the children. The quest narrative was influenced greatly by participants’ religious beliefs and the want for societal change with regards to attitudinal barriers such as stereotyping and institutional barriers with regards to barriers to educational institutions, healthcare institutions and access to public monetary benefits. However, like the other two typologies, complexities and nuances also existed within the quest narrative and how they played out for the participant groups. It was also observed that the quest narrative presented more complexities and nuances compared to the other two narratives. Furthermore, of the three categories of the quest narrative, participants constructed stories that only enacted the *auto-mythology* and the *manifesto* but not the *memoir*. It was also evident that the quest narrative was dominated by the views of parents and the extended family and siblings had less to say in this narrative.

8.5.1 The auto-mythology

The enactment of the quest auto-mythology by study participants appeared to be underpinned by their religious beliefs. Through these, they employed romanticism to describe how they had made sense of the children having cerebral palsy, making the experience appear better than it seemed. Under this, participants attributed their children having cerebral palsy to the will of God and as a means of God testing their faith. However, in this narrative turn, some complexities existed in how participants

constructed this narrative. Discrepancies were observed between how this narrative was constructed when participants tried to present some reasons to justify why cerebral palsy was the will of God. Siblings appeared to offer no justification as to why cerebral palsy was the will of God. However, mothers, fathers, and extended family members seemed to agree that the children were given as gifts through the will of God. Furthermore, some mothers considered that the children were given through God's will to strengthen the bond that existed with their partners. The extended family members involved in this study appeared to present contradicting perspectives. While the extended family group believed with the other family member groups that the children were destined to have cerebral palsy through God's will (i.e. it was a predetermined occurrence by God) they also held a contradictory perception that cerebral palsy was punishment for the sins of the parents. They seemed to believe that there could be hidden sins on the part of the parents for which God was punishing them.

Another meaning constructed by the majority of participants was that it was a test from God. This was the construction of parents though dominated by fathers with the extended family and siblings silent on this perception. It appeared siblings and the extended family groups seemed to have exited the quest auto-mythology narrative when they seemed to share the common opinion with parents that cerebral palsy was the will of God. After this, they entered the *Manifesto*. However, parents remained with the auto-mythology narrative constructing cerebral palsy as a test of their faith from God. This perception of cerebral palsy as a test from God appeared to be underpinned by religious readings that the parents had taken from the Bible and they quoted verses from the Bible to justify this. Parents exited the auto-mythology at this point. In summary, while parents held a dual perspective within the auto-mythology narrative that cerebral palsy was both "the will of God" and "a test from God", siblings and extended family members held a single view that cerebral palsy was only "the will of God".

8.5.2 The manifesto

Participants in this study constructed this narrative type when it appeared they wanted social action with respect to attitudinal barriers and institutional barriers that children with cerebral palsy and their family members encounter frequently. All participants

were quite positive that if people were educated more about cerebral palsy and especially about the long-term nature of the condition, stereotypical attitudes, stigma and ostracism among others, that they experienced frequently, could be eradicated from society or reduced to the minimal.

Participants further enacted the quest manifesto when they called for the removal of institutional barriers that worked to the disadvantage of their children. However, there was a dominance of parents' views with regards to this narrative with feelings that their children were losing societal opportunities; they especially expressed that if barriers to inclusive education and healthcare were removed and access to social services and monetary benefits be improved, these children and their families would fare better. Participants, therefore, called on stakeholders such as the government, NGOs and other interested organisations to help effect the needed changes they so wanted.

8.6 Conclusion

This chapter has attempted to pull the findings of this study together and has also highlighted the narrative dominance as well as the narrative movements and timelines by underpinning the movements with the Kaleidoscope metaphor. The nuanced differences and complexities existing between participant groups have also been highlighted. In conclusion, all participants constructed the same narratives of restitution, chaos and quest with no major distinctions between the contents of the narratives for each participant group. However, subtle or nuanced distinctions were observed which were mostly embedded in narrative dominance, narrative movement and narrative timelines. A discussion of the study findings, comparing and contrasting them with the existing literature and the literature on Frank's narrative typologies will be presented in the next chapter.

CHAPTER NINE: DISCUSSIONS AND CONCLUSIONS

9.1 Introduction

It has been the argument of this thesis that the study of the experiences of family members living with children with cerebral palsy have mostly centred on the mother and the voices of significant others are less heard or almost left out. The study proposed that studying cerebral palsy experiences by adopting a multi-participant perspective could bring a holistic understanding of this experience. The research question and objectives of this study as proposed both at the latter part of chapter two (2.14 and 2.14.1), and within the methodology sections, have therefore been answered by: reporting study findings from different groups of family members connected to the lives of children with cerebral palsy, and meanings and interpretations having been drawn from the cerebral palsy experience underpinned by Frank's narrative types.

Though family members from the different heterogeneous groups of participants presented their own experiences of living with children having cerebral palsy, there were shared characteristics, opinions and views that led to a consistent identification of Frank's narrative typologies of restitution, chaos and quest, in their stories. Previous literature (Bally et al., 2014, Diver et al., 2013a, Ezzy, 2000, France et al., 2013, Nettleton et al., 2004, Reynolds and Vivat, 2006, Soundy et al., 2010, Thomas-MacLean, 2004, Travers and Lawler, 2008, Vroman et al., 2009, Whitehead, 2006) which has used Frank's narrative typologies has considered mostly the experiences of the ill person, leaving the experiences of their family members unexplored. This study provides novel data which adds to and further extends Frank's typologies, presenting evidence that family members, like the chronically ill person, present experiences that fit the narratives of quest, restitution and chaos.

Issues underpinning the illness narratives in this study were help-seeking behaviour and hope for cure, belief in the supernatural (mystery and spiritualism), social stigma, isolation, financial issues and religious beliefs. This chapter will re-examine the study findings by comparing and contrasting with the existing literature on Frank's narrative types (which will be briefly introduced in this chapter as this literature evolved during data analysis) and the wider literature on cerebral palsy and disabilities. This will demonstrate that the experience of living with children who have cerebral palsy could

be considered using the narrative typologies of Frank as it provides a model for understanding this experience. In this chapter also, the relevance of this study to healthcare practice will be discussed and recommendations for further research made.

9.2 Frank's Illness Narratives

The subjective experience of illness has been increasingly studied by utilising narrative theory (Kleinman, 1988, Hassin, 1994, Frank, 1995, Mattingly and Garro, 2000) Polkinghorne suggested that narratives provide the primary scheme through which "human existence is rendered meaningful" (Polkinghorne, 1988) whilst Mattingly extended this to the illness experience in particular (Mattingly and Garro, 2000). Recent empirical studies on illness narratives have sought to explore the factors that are involved in shaping a story, stories and their therapeutic value on the teller and the ownership of stories (Murray, 2000). Adopting the concept "narrative types", Frank describes three types of narratives pertaining to illness in his book *The Wounded Story Teller* (Frank, 1995). Frank (1995) explained his narrative type to be the most general storyline that can be recognized underlying the plot and tensions of particular stories. Frank further posited that stories are individualistic, but people compose their stories by the adaptation and combination of narrative types made available by cultures. His classification of illness stories is not meant to simplify their complexity but rather to illuminate the types of stories and to enhance their understanding. Given their inherently complex nature, however, Frank (1995), strongly believed that all three typologies would find themselves in any type of illness stories both alternatively and repeatedly, mimicking the patterns in a Kaleidoscope. Frank believes that stories are fluid and continually unfold but nonetheless, his narrative types provide accessible entry points to narrative analysis without being cumbersome (Thomas-MacLean, 2004). The use of narrative thematic analysis in light of Frank's narratives anchored this study and has led to the development of a depth of understanding in living with children with cerebral palsy in the family. Though thematic analysis was employed as a stand-alone analysis at the initial phase of analysis, findings largely reflected the existing literature review. Furthermore, interpretation of the findings in order to bring out a theoretical understanding, as one of the objectives of this study, became difficult and challenging using thematic analysis alone. Some scholars (Gibson and Brown, 2009, Willig, 2013) have criticised the use of thematic analysis as a stand-alone analysis in research. They have argued that thematic analysis is not a fully-fledged

method on its own and therefore must not be used as a specific analytic approach but must rather be used as a meta-analytic technique to underpin other analytic approaches in the identification of patterns and themes only (Gibson and Brown, 2009, Willig, 2013) . It appears this research validates this critique on thematic analysis as it could only be used in the identification of patterns and formation of themes and not theoretical explanations of the themes developed. The use of Frank's narratives therefore enhanced the interpretation of themes and the development of theoretical understanding.

9.3 Existing literature on Frank's narratives

A total of 11 studies (Bally et al., 2014, Diver et al., 2013a, Ezzy, 2000, France et al., 2013, Nettleton et al., 2004, Pinnock et al., 2011, Reynolds and Vivat, 2006, Thomas-MacLean, 2004, Travers and Lawler, 2008, Vroman et al., 2009, Whitehead, 2006) have constructed illness narratives of individuals in light of Frank's narrative typologies. The table at Appendix 8 demonstrates the existing literature on Frank's narratives). Six of these studies (Diver et al., 2013a, France et al., 2013, Nettleton et al., 2004, Pinnock et al., 2011, Reynolds and Vivat, 2006, Whitehead, 2006) were conducted in the United Kingdom, Two (Ezzy, 2000, Travers and Lawler, 2008) were from Australia, another two (Bally et al., 2014, Thomas-MacLean, 2004) were from Canada and the last one (Vroman et al., 2009) was conducted in the United States of America.

The conduct of these studies in only developed settings or Western countries, with more than half of these studies coming from the United Kingdom, raises the question of transferability to developing settings given the differences in culture, economy, beliefs, social and religious values and experiences. This study thus fills the gap by highlighting and illuminating illness narratives from developed settings and appears to be the only study that has focused on the illness experiences of people living with the chronically ill child.

Furthermore, It is also very interesting to observe that with the exception of two studies (Bally et al., 2014, Pinnock et al., 2011) whose authors considered the experiences of members surrounding the ill person all the other 9 studies have constructed illness narratives based on the experiences of the ill person only, whiles that of the members living with and caring for the ill person have been largely neglected. For Pinnock et al

(2011), the researchers considered the experiences of the ill person in addition to informal carers (family members, friends or neighbours). However, the researchers generalised the number of informal carers involved in the study, hence, the number of family members that participated were not clarified. Hence, the voices of the family members who might have taken part in this study were lost in literature. In contrast, the current study has focused on the experiences of family members and has been explicit about which family members have been included in the study and have also brought out the voices of these family members. Moreover, Pinnock et al (2011) reported that persons caring for the ill person constructed chaos stories only, which is inconsistent with the findings of this study. Again, in contrast to this study which focused on childhood chronic illness, Pinnock et al (2011) focused on adult chronic illness. This study is thus the first to contest with evidence that all the illness typologies of Frank were constructed by family members surrounding the chronically ill as far as chronic illnesses are concerned.

Even though Bally et al (2014), who studied the experiences of families living with children with cancer, considered the experiences of parents, their study was biased towards mothers as they involved 12 mothers and only 4 fathers in their studies neglecting other significant members in the family. Moreover, childhood cancer, through current medical advances, has the potential of been cured and hence its chronicity has been challenged. Bally et. al (2014) also reported restitution and chaos dominated the stories of parents having children with childhood cancer and quest stories were less or almost non-existent. Therefore, the findings of the current study, with regards to the illness narratives of persons surrounding the chronically ill child, still contend as novel, being the first study on childhood chronic illness to have detected the presence of all Frank's narratives as dominant. However, the findings from Bally et al (2014) who reported that parents of children with childhood cancer, constructed restitution, chaos and less of quest, still provide an empirical reinforcement to the findings of this study, that persons surrounding the ill person, and for that matter, the chronically ill would construct restitution, chaos and quest stories.

It could be understandable why almost all the existing narratives on Frank's narrative forms might have largely neglected the experiences of persons living with the ill person, due to independent living that is mostly encouraged in the West or developed countries. This could also mean that the ill person may not be dependent upon any

family member. However, in less developed settings like Africa and other areas, where family and community living are largely practised, it is very common to find both the nuclear and extended families living together with the chronically ill child. It is therefore expedient that the experiences of the persons living with the chronically ill child are registered in literature to inform medical practice in underdeveloped contexts. The current study, as one of its major strengths and novel findings, has endeavoured to fill this gap by highlighting and demonstrating the experiences of people living with the chronically ill child and asserts that the narratives of restitution, chaos, and quest do not only constitute the stories of the ill person only but the stories of family members as well. However, more research would be needed in this area to confirm the findings of this study and to also look at the narratives of people living with individuals with other chronic illnesses in underdeveloped contexts.

An observation made by the current study is that there appeared to be no major differences among participant narratives, except some few nuanced complexities, with regards to how the illness narratives of restitution, quest and chaos played out for the heterogeneous groups of participants. This finding was also consistent with those of Bally et al (2014), who suggested that no differences existed in the narratives of restitution, chaos and quest constructed by Mothers or Fathers. Thus, these findings from the existing literature may help support the results evidenced in the current study, that no major differences may be observed between the narratives of participants sharing the same experience albeit they may belong to different heterogeneous groups. However, that notwithstanding, the current study has endeavoured to highlight the subtle and nuanced differences in narratives between different heterogeneous groups constructing Frank's narratives and has highlighted that these subtle differences may be embedded in narrative timelines, dominance and movements as elaborated at the triangulation chapter. This is a new finding that adds on to the existing literature.

Furthermore, the finding that there were no major differences between the narratives of family members in the current study, also reflected a study conducted on ill persons themselves utilising Frank's narratives. France et al (2013) who studied the accounts of men and women surviving stroke reported stories of quest, restitution and chaos. As the main objective of the study, the researchers (France et al., 2013) had aimed to

find out the different narrative genres that could be available to men and women in light of Frank's narratives. From the literature review conducted on existing studies utilising Frank's narratives as an explanatory model, it appeared that until the year 2013, when France et al. (2013) conducted a study to find out the narrative genres that might be available to men and women, none of the studies conducted before this time, had considered the differences in the narrative genres between men and women, albeit almost all the studies that had been conducted so far, had involved both the male and female gender in their studies. The researchers (France et al., 2013), therefore suspected women and men might have different narrative genres available to them based on the assertion that their experiences of chronic illness might differ. However, France et al. (2013) reported that there were no observable or apparent differences in the narrative genres reported by study respondents.

The use of Frank's narrative typologies in understanding the experiences of family members surrounding children with cerebral palsy is unique as no work on Frank's typology has been done utilising this perspective. The results of this study, therefore, offer a new model for understanding what it is like to live with a child having a chronic condition. The next sections would compare and contrast the findings of this study to the existing literature on Frank's narratives with regards to the findings and contents of restitution, chaos and quest. The findings from this study will also show that the narratives of family members also reflect data from literature which has utilised Frank's narratives to explore the views of ill patients themselves. The larger literature on cerebral palsy conducted in chapter 2 will also be compared and contrasted with the findings of this study and where necessary, the larger literature on disability.

9.4 Restitution

Having its basic narrative plotline as "yesterday I was healthy, today I am sick but tomorrow I will be better", the restitution narrative has been framed as the most common narrative among people with recent illness and may be less evident among the chronically ill (Frank, 1995, Whitehead, 2006, Frank, 2013). The restitution narrative demonstrates a movement away from an optimal state of health, coming back again to the optimum and explores the experiences encountered within health investigations and treatments. The desire for restitution to occur by the ill person is compounded by other people's expectations to hear restitution stories. The

institutional stories of illness have affected people's expectations of how stories of illness should be told (Frank, 2013). The various mass media portray the stories of people who have recovered from illness and continue to live normal lives (Frank, 2013, Kroll-Smith, 2003, Whitehead, 2006). The restitution narrative thus reflects a modernist expectation that "for every illness, there is an equal remedy" (Diver et al., 2013a, Frank, 1995, Frank, 2013, Whitehead, 2006)

Results from the current study have demonstrated that all study participants from the heterogeneous groups, commenced their illness narratives with the restitution typology and this narrative appeared to be the most desired by study participants as their desire for restitution never went away. This narrative was evidenced at the pre-diagnosis stage, after diagnosis, seeking treatment and when participants came to the realisation that both biomedical and traditional treatment had failed and therefore resorted to religious beliefs for cure. Restitution in the current study was therefore underpinned by help-seeking behaviour and belief in transcendence for a desired cure.

The current study has demonstrated that restitution first emerged at the pre-diagnosis stage when study participants perceived that "something was wrong" with the children. This result shows consistency with the narratives of parents having children with cancer (Bally et al., 2014). However, this differs from the reports of chronically ill people themselves where inconsistencies in the emergence of restitution narrative have been detected. In a report of people with Fibromyalgia Syndrome (Diver et al., 2013a), it was observed that all participants began with restitution narrative at the onset of their symptoms during the pre-diagnosis stage. However, this was not the case for people suffering from cancer (Thomas-Maclean, 2004) or HIV (Ezzy, 2003).

In the present study, participants did not initially consider the children's condition to be long term as they believed the condition could be resolved within the biomedical means like any other acute illness. This finding was replicated in the restitution narrative of parents living with children with childhood cancer, where parents perceived that there was something wrong with their children and anticipated that their children's condition could be resolved after biomedical consultations (Bally et al., 2014). This finding also reflects the results of people living with chronic fatigue syndrome/myalgic encephalomyelitis (Whitehead, 2006) and people with fibromyalgia

(Diver et al., 2013) where participants reported that at the onset of illness, symptoms seemed familiar and unthreatening.

The current study has evidenced that during the pre-diagnosis phase of restitution, family members reported a delay in the child's developmental milestones and they sought to find explanations mostly within the biomedical model in order to establish what could be wrong with the children and find possible cure. Children were therefore mostly sent to health facilities to access biomedical assessments, find out the diagnostic label of the condition and access possible treatment. This finding aligns with those with chronic obstructive pulmonary disease (COPD) in a similar way (Pinnock et al., 2011). For those with COPD, it appeared that during the time when it was suspected that something was wrong, participants told illness narratives of restitution, of being increasingly breathless and rushed to health facilities for biomedical assessments, possible diagnosis and treatment or referral for assessment for lung transplantation (Pinnock et al., 2011). However, the current study has highlighted a possible division of the restitution narrative into Passive and Active restitution in accordance with the enactment of the restitution narrative by participants during the pre-diagnosis and diagnosis stages. This finding is unique to this study as it is not existent in previous literature. The current study has demonstrated that parents participated actively in biomedical consultations in the hope of achieving restitution while siblings and the extended family participated passively by not engaging in biomedical consultations but however demonstrated the belief that restitution would happen for the children. Thus, for family members living with childhood chronic conditions, restitution could be passive or active at the onset of the child's condition based on their closeness to the child with the chronic condition. Furthermore, the actions of family members in this study (where the restitution narrative dominated) also reflected the tenets of the medical model of disability (section 1.1.11.1) in which disability is conceptualised as a biological or medical problem. It appears family members conceptualised the children's condition as a medical problem which needed to be corrected, hence their endeavour to seek restitution within the biomedical model of cure. In the current study, restitution became a secondary narrative with chaos assuming the primary when at the point of diagnosis; participants expressed feelings that mainly depicted the chaos narrative plotline. At this point, participants exhibited a decrease belief in the biomedical model upon knowing about the prognosis for cerebral

palsy. This finding demonstrated Frank's view about the smooth and chronological movement of restitution narratives whilst components of other narratives may intrude at some point. Gaining a diagnostic label and professional explanation to the children's condition were significant points within the experiences of participants, as it appeared restitution was further relegated to the background and chaos becoming the main narrative. However, chaos at the point of diagnosis was short-lived as there was the re-emergence of restitution when participants learned about the available rehabilitation support for the children. Restitution became the foreground narrative again as it appeared their hope in the biomedical model had been revamped. This finding compares similarly to the restitution narrative of those living with chronic fatigue syndrome/fibromyalgia at the time of diagnosis (Whitehead, 2006). In whitehead's study, the participants divided into two pathways during the time of diagnosis: those who searched for diagnosis themselves and those for whom the diagnosis was medically led. The results were that those whose diagnosis was medically led presented a shorter chaos narrative, as restitution re-emerged after knowing about the prognosis of fibromyalgia, a finding which similarly compares with the current finding.

The failure of biomedical treatment in providing the desired restitution led participants to consider an alternative means of seeking restitution for the children. Herbalism was engaged to complement biomedical treatment, with the hope that in lieu of biomedical treatment, alternative or the traditional approach to treatment could bring restitution into effect. This action further deepened the participant's desire for restitution to happen. Participants did not disclose the alternative source of help they sought to health professionals.

The use of herbalism as an alternative treatment in this current study and the hope that participants demonstrated in herbalism to bring about cure is not surprising as it has a contextual explanation. Previous research has demonstrated that in developing contexts, especially Africa, herbal remedies, contextually called traditional medicines are often preferred over treatments recommended by cosmopolitan or western medicine (Abdullahi, 2011, Amoah et al., 2014) because of easier accessibility to these treatments and their associated low prices or cost and also due to the general perception that traditional treatments are harmless and are guaranteed to bring favourable results (Abdullahi, 2011). In Africa, the preference for traditional medicines may also be related to personal beliefs and the different ways of understanding the

health-disease process which is different culturally from those of western medicine. Within the African culture, traditionally based therapeutic practices that employ mainly the use of herbs or medicinal plants are sometimes also associated with secret rituals which are mostly performed by practitioners who are deemed to hold the necessary knowledge for cure (Abdullahi, 2011, Amoah et al., 2014). It has been estimated empirically that in Ghana, around 70% of healthcare is provided by traditional healers who have no formal training and that “there is an estimated one traditional healer for every 400 inhabitants and one physician with conventional medical training for every 12,100 inhabitants” (Abdullahi, 2011, Amoah et al., 2014). In Ghana, traditional medicines are created by ordinary people and forms part of their way of life (Abdullahi, 2011, Yeboah, 2000). Furthermore, there is a high preference for traditional treatment over modern medicine and this is usually so due to the general misconception that traditional medical healers have spiritual powers, have medicines that can cure any kind of diseases including those that are deemed chronic by the medical world. The audio and visual media have also helped in the promotion of traditional medicines because traditional medicine practitioners and purveyors are allowed to advertise their products on these media for a small fee. Many times, in a bid to reinforce the potency of their plant-based medicines, herbalists would bring some people who they would portray as their past patients, to testify about their products and how the products have helped with their healing. This practice in the Ghanaian setting seems to reinforce Frank’s (1995) view that the mass media helps in the propagation of the restitution narrative. These traditional healers or herbalists have no formal training in the use of traditional medicines yet people trust in their expertise for healing and it has, therefore, become a self-mandate for biomedical practitioners to advise against consultations with traditional healers and frequently warn patients and their carers that traditional healers rather aggravate medical conditions instead of offering cure. However, the current study reveals that such warnings and advice from professionals are not heeded due to the desire for restitution to happen by any means and this even poses a potential threat to biomedical practice in the country with regards to management of chronic conditions as it appeared some participants gave more credence to traditional medicine over conventional practice by attributing some improvements they had observed in the children to traditional treatment. This could mean that in future people may focus more on traditional treatment as far as the management of chronic conditions is concerned, with the hope that the ill person could be cured. This also

portrays a lack of knowledge about chronic conditions and their long-term nature. Previous research that relates to the enactment of the restitution narrative by ill persons, provides further evidence on how chronically ill persons demonstrated an alternative help-seeking behaviour within the restitution narrative which reflects the current finding (Whitehead, 2006). For those with chronic fatigue syndrome/ myalgic encephalomyelitis (CFS/ME), the use of alternative therapies was widespread after the establishment of diagnosis. All participants tried a form of complementary/alternative treatment and several therapies (Whitehead, 2006). However, while the current study demonstrated that herbalism was the main form of alternative treatment for participants, Whitehead (2006) discovered that diets in the form of wheat-free, sugar-free, no meat, no dairy products and a high potassium diet, were the most common form of alternative treatment for those with CFS/ME.

There exists literature evidence in the practice of religious beliefs and rituals believed by some people to elicit the intervention of that which is divine, in causing spiritual and physical healing, especially in Christian practice, which are reflected in the findings of the current study when both biomedical and alternative sources had failed to provide the cure participants had expected. There is the assertion by believers that by religious faith through prayer and/or other rituals such as laying on of hands, a divine presence and power could be stimulated to bring about the healing of disease and disability (Village, 2005). Furthermore, there have been popular claims that numerous religious rituals such as prayer, intervention from the divine, or an individual healer's ministrations can bring about healing or cure illness (Barrett, 2005). According to the American Cancer Society, many people have expressed claims that faith and prayer can cure chronic conditions such as multiple sclerosis, blindness, deafness, defective speech, cancer, many developmental disorders, Acquired Immune Deficiency Syndrome (AIDS), etc. and recoveries from these have been attributed to many religious techniques which have been classified commonly as faith healing (Bannister, 2015). Faith healing can involve a strong belief in a higher power or a supreme being for cure, prayer or a visit to a religious shrine to perform some rituals (Bannister, 2015). The New Testament of the Bible has been interpreted by many Christians as a canon which teaches a belief in and practice of faith healing and a study among some Americans found that participants believed praying to God can cure the ill person regardless of the claims of medical science that the condition is incurable (Gansler et

al., 2008, Kalb, 2003). Furthermore, an author who probed into the increasing knowledge about divine healing within the leadership of an immigrant religious establishment, reported that some Muslims exercised the claim that the Quran is not only a revelation about God but it was also sent as a medical potion to heal, and they believed that it can totally cure any physical or spiritual illness through religious rituals such as reciting the words of the book (Quran) over water or reciting it over olive oil and drinking the water or anointing oneself with the oil. Muslims also claim that through a ritual called *ruqyah* in which the right hand is placed on the forehead or at the site of illness and certain words from the Quran classified as *Sura Al-Fatiha* are then recited, illness can be cured (Haokip, 2007). The present study has demonstrated that as both biomedical and traditional medicine failed in bringing about the expected cure, participants felt they had exhausted all avenues for healing and felt there was nothing they could do in their power to bring about restitution. From thenceforth, it emerged that participants had begun trusting in a supreme being or in a higher power for cure, a finding which is reflected in the existing literature about religious beliefs for cure. It appeared they had lost hope in any human intervention and expressed a belief in transcendence for cure, a cure that was beyond the normal physical human experience. This hope for cure was underpinned or stemmed from religious readings about people being cured miraculously. Almost all participants in the current study subscribed to either Christianity or the Islamic religion and to bring about this transcendent belief for cure, both Christian and Muslim participants engaged in daily rituals of praying to a higher power to have mercy on their children and heal them. Members demonstrated a capacity to maintain hope in God for cure even with the increasing realisation that such hope of their children recovering would not occur. Not only does this finding reinforces the existing literature about the religious beliefs of chronic illness but also reflects a change from a “treatment” (alternative or conventional) to a belief in God’s will. This finding, therefore, provides an extension to what Frank and others describe as a cure in the restitution narrative model. This study, therefore, extends the restitution narrative to include transcendent beliefs for cure.

9.5 Chaos

In the chaos narrative, the plotline is that life will never get better and that no one is in control. Frank (1995, p.101) describes sufferers in the chaos narrative as experiencing “emotional battering” which stems from a rejection of their suffering clinically by

clinicians and socially by others. Within the current study on the experiences of family members having children with cerebral palsy, the chaos stories shared mostly demonstrated a loss of control. Mothers, fathers, siblings and the extended family members interviewed, all told chaos stories that had an intermittent occurrence through their experiences of living with children with cerebral palsy.

In the current study, chaos initially occurred both at the period of diagnosis and the period immediately following diagnosis as all participants became aware of the long-term nature of cerebral palsy. The emergence of chaos after diagnosis is in contrast to the study on Fibromyalgia syndrome which reported that chaos had an initial emergence during the pre-diagnosis period (Diver et al., 2013a). Furthermore, while one study (Pinnock et al., 2011) reported that it wasn't clear when chaos emerged and that the chaos narrative of participants living with COPD lacked a clear beginning, an unpredictable and unanticipated end, another study (Thomas-MacLean, 2004) found that chaos was contained within the other two forms and its emergence wasn't clear cut. All other studies (Bally et al., 2014, Ezzy, 2000, France et al., 2013, Nettleton et al., 2004, Reynolds and Vivat, 2006, Travers and Lawler, 2008, Vroman et al., 2009, Whitehead, 2006) using Frank's narratives did not report the initial emergence of chaos.

The current study has identified that diagnosis and the period afterward plunged participants into chaotic emotional situations characterised by a great disturbance, confusion, shock, grief and a profound sense of loss of control and a great uncertainty about what the future holds. Though such emotional experiences were dominated by parents, that notwithstanding, siblings and extended family members also responded emotionally when they knew about the long-term nature of cerebral palsy. These findings at the time that the chaos narrative emerged had similar occurrences in other studies which reflects the findings of the current study. Men and women who were diagnosed with stroke (France et al., 2013) enacted the chaos narrative as they described emotional suffering, traumatic and disempowering experiences in the hospital after diagnosis and felt a loss of control. In the chaos narratives of patients living and dying with severe chronic obstructive pulmonary disease (COPD), being diagnosed was interpreted as shocking and chaotic by the ill person and family members (Pinnock et al., 2011). Linear chaos narratives at the time of diagnosis were characterised by expressions of anger and depression intermingled with attempts to

avoid or deny these emotions in those having HIV (Ezzy, 2000). From a study on the parental experiences of living with children with cancer (Bally et al., 2014), it emerged that the time of diagnosis and the period after diagnosis led to the enactment of the chaos narrative characterised by doubt and uncertainty about the children's future, anxiety-provoking thoughts, lack of control and fear about the future of their children. It came out the parents required time and space to reflect to hone their thoughts and reflect upon the life-changing event that they encountered when their children were diagnosed with cancer and this rendered restitution or quest narrative impossible to be enacted at the time of diagnosis but rather chaos.

Further evidences (de Aguiar Lélis and Cardoso, 2014, Dehghan et al., 2015a, Fernández-Alcántara et al., 2013, Huang et al., 2010b, Kruijsen-Terpstra et al., 2016a, Milbrath et al., 2008b, Whittingham et al., 2013a) to support the emotional experiences occurring at the time of diagnosis have been identified in the wider literature about the experiences of having children with cerebral palsy which further reinforces the findings of the current study. At the time of diagnosis, mothers felt they had lost the ideal child, lost normal motherhood and a loss of giving birth to a healthy child which society normally expects (de Aguiar Lélis and Cardoso, 2014, Huang et al., 2010b). Greatest moments of emotional distress, which include trauma, shock, are expressed by parents when children are diagnosed with cerebral palsy after birth and some would express denial that their children had no cerebral palsy. (Fernández-Alcántara et al., 2013, Whittingham et al., 2013a). Mothers expressed sorrow and desperation which increased when they began to assimilate the news about the loss of the child they anticipated (Fernández-Alcántara et al., 2013). At the time of diagnosis, some mothers underwent mixed feelings characterised by rejection, sadness, self-blame and felt great uncertainty about the future of their children (Huang et al., 2010b).

Furthermore, it was evident in the chaos narrative, as a significant finding in the current study, that some participants blamed healthcare professionals after diagnosis, when the nature of cerebral palsy was realised, with participants expressing the feeling that professionals were potential contributors to the cause of cerebral palsy in their children, through what they perceived as medical negligence and inappropriate conduction of some medical procedures. This finding appears to be implicitly reflected in the chaos narrative of those living with chronic fatigue syndrome/myalgic encephalomyelitis (Whitehead, 2006) and in the narratives of those living with acute

and chronic low back pain (Vroman et al., 2009). Half of the participants living with myalgic encephalomyelitis reported they felt their GPs were not supportive and this they felt was a setback that kept them in the cycle of the chaos narrative. (Whitehead, 2006). In those living with low back pain, the distress and frustration experienced through biomedical interactions with health professionals, caused them to question the authenticity of the low back pain they were diagnosed with. Their interactions with medical providers were mingled with scepticism, pessimism and their expectations in receiving effective treatment from medical providers were very low. (Vroman et al., 2009). These participants further intimated that they were not always in receipt of the treatment they desired or deserved and what they perceived as a vague diagnosis from health professionals caused them much distress. They, therefore, demonstrated a lack of confidence in the biomedical healthcare professionals abilities to understand and effectively treat their condition (Vroman et al., 2009). This finding in the current study also shares some similar characteristics with a study in the wider literature (Huang et al., 2010b) about the experiences of living with children with cerebral palsy. It has been reported how mothers cited different reasons to blame healthcare professionals upon knowing about the long-term nature of cerebral palsy after their children were being diagnosed. Mothers of the children with cerebral palsy felt healthcare professionals exhibited an attitude of carelessness or their knowledge about cerebral palsy was insufficient to ensure that their children received correct medical assessment and diagnosis and they further lost their trust in professionals with regards to their ability to make care decisions (Huang et al., 2010b). For some mothers in the study, the diagnosis of their children was delayed until a later time because of their distrust in healthcare professionals and even after diagnosis, they opined that the professionals failed to conduct thorough and careful physical examinations and they reported the professionals even failed to suggest seeking further opinions elsewhere. However, other findings (Hayles et al., 2015b, Kruijssen-Terpstra et al., 2016a) which contrast the findings of the current study and that of Huang et. al (2010b) have also been presented. These researchers reported how parents demonstrated a great reliance on healthcare professionals and often expected information from these professionals regarding the general nature of cerebral palsy, the child's therapy, management of the child's condition and what they were to expect for the future of the child (Hayles et al., 2015b, Kruijssen-Terpstra et al., 2016a). The interventions concerning the children's condition were often done through a built

partnership between parents and health professionals and the growth of this partnership was dependent on both parents and therapists (Hayles et al., 2015b, Kruijssen-Terpstra et al., 2016a). Other studies have however presented parents' experiences after diagnosis as a situation of ambivalence. They reported that mothers portrayed vulnerability in handling the children's condition and were therefore dependent on the competence of healthcare professionals while at the same time doubted whether these professionals would be able to take care of the specific needs of their children (Iversen et al., 2013b, Whittingham et al., 2011a).

Participants blaming healthcare professionals and further perceiving that they could be potential contributors to cerebral palsy, and other study subjects distrusting health professionals after the children had been diagnosed of cerebral palsy, as reported by others (Huang et al., 2010b) could be understood as a loss of control of the children's condition as proposed by Frank. It appears cerebral palsy diagnosis and a knowledge about the true nature of cerebral palsy represents a period of grief in which family members, especially parents, appear to feel that they had lost the ideal child they expected. This reaction portrayed by participants also appears to reflect some characteristics of grief as proposed by Elisabeth Kubler-Ross and David Kessler in their classical work on finding the meaning of grief (Kübler-Ross and Kessler, 2005). The writers proposed that the five stages of grief include denial, anger, bargaining, depression and acceptance and these represent how individuals are able to learn to live with what they have lost (Kübler-Ross and Kessler, 2005). The denial stage helps people to survive the loss and this stage is represented by meaninglessness and overwhelming expressions. It basically represents a stage of shock and denial. The anger stage represents a healing process, feeling your anger even though it may seem endless. The bargaining stage seems that an individual would do anything to restore the condition of the loved one and want life returned to what it was. After bargaining, there is a return of emotions to the present, characterised by feelings of emptiness, and grief enters on a deeper level; this represents the depression stage. The acceptance stage deals with recognising that the loved one is physically gone or lost forever (Kübler-Ross and Kessler, 2005). Though the proponents of the five stages of grief based it mainly on the loss or death of a loved one, it appears participants in the current study exhibited the characteristics of grief through anger after their children were diagnosed with cerebral palsy when they felt health professionals involved in the

delivery of the children or who carried out some medical procedures earlier on in the children's life could have contributed to the children having cerebral palsy and as a result blamed health professionals as potential contributors to cerebral palsy, upon realising that cerebral palsy could not be cured. Grieving through denial could also be evident in the work of Huang et. al (2010b) when parents felt that health professionals did not conduct thorough examinations after their children were diagnosed with cerebral palsy. It appeared they were in denial that their children had been diagnosed with cerebral palsy. It would also then appear that parents who portrayed a strong reliance and partnership with healthcare professionals in the daily management of the children's condition as reported by other authors (Hayles et al., 2015b, Kruijssen-Terpstra et al., 2016a) might have reached the acceptance stage of grief in which they had accepted the diagnosis and explanations from professionals and were learning ways of living with the condition, and in this, they felt the need of partnership with healthcare professionals. This raises the need for chaos stories to be listened to in the case of those living with children with cerebral palsy particularly in relation to helping with the grieving process and augmenting or helping with faster healing after knowing about the nature of cerebral palsy. It appears there is the need for some form of forum for these stories to be told or to make public accounts of chaos stories in order to allow the acceptance of this narrative as denying such stories would mean a neglect of the feelings of those who are suffering it. In this, healthcare professionals have a role to play as they could use listening as a therapy by entering into a relationship with clients or in this case, family members, which is based on listening to their stories to help with their healing. Without an opportunity for chaos stories to be heard, it is likely or possible that healing may be denied.

The current study has demonstrated that chaos became the dominant narrative and restitution was relegated to the background as participants realised that both biomedical and alternative treatment had failed to provide cure. This period was characterised by a loss of control of the children's condition compounded by the feeling that there was no other alternative. Participants, therefore, felt that nothing would help again. The narratives of participants at this period were therefore engrossed in the chaos narrative. From this point, participants reported chaos stories that were rooted in cultural beliefs underpinned by mystery, superstition and spiritualism. Their stories of mystery, superstition and spiritualism mainly reflected a demonization of illness

described by Frank and other authors which occurs within the chaos narrative (France et al., 2013, Frank, 2013). It appeared participants and the larger society believed that cerebral palsy was the work of demons, the reason it could not be remedied despite the efforts they made for restitution to be achieved. The demonization of illness based on mystery, superstition and spiritualism as evidenced in this study tends to reflect beliefs about the causation of illness described by some authors (Alexander and Selesnick, 1966, Hamel, 2015, Harpur, 2013, Koenig, 2009, Porter, 1999) that are embedded in the cultural model of disability (section 1.1.11.3). It has been reported that ancient peoples of various religions and cultures such as the Egyptians and the Babylonians, associated illness and different types of diseases with demonic activity (Alexander and Selesnick, 1966). In the book *The History of Psychiatry*, Franz Alexander (Alexander and Selesnick, 1966), author and medical doctor, indicated that in such ancient cultures people believed their spiritual world was populated with demons of varying degrees of power who caused different diseases and even death. It appears that when participants in this study talked about the cause of cerebral palsy after both biomedical and alternative consultations had proved futile, they seemed to believe that mystery, superstition and spiritualism, had a part to play. This finding suggests lack of knowledge about cerebral palsy in the Ghanaian culture. A lack of knowledge about disabilities has been reported in the African population and is considered deeply rooted in the culture of the people (Kromberg et al., 2008, Stone-MacDonald and Butera, 2012, Munyi, 2012). In this culture, the aetiology of disabilities has been associated with superstitious beliefs such as the breaking of taboos (e.g. breaking polygamy rules, not honouring the rights of first and second wives), witchcraft, mother's unhappiness, fate, consanguinity, inheritance, sorcery, bad experiences with animals such as snakes, sex-linked factors and supernatural forces (Kromberg et al., 2008, Munyi, 2012). An interpretive literature review (Stone-MacDonald and Butera, 2012) which examined beliefs about the causes of disability in East Africa reported that the causes of disabilities were mostly grounded in mystery and superstition and were often described or expressed in proverbs, folktales and oral traditions (Stone-MacDonald and Butera, 2012). This review found that people attributed the causes of cerebral palsy to witchcraft, evil or bad spirits and disobedience to cultural taboos. There were also the descriptions of some taboos that when broken were thought could cause disabilities (Stone-MacDonald and Butera, 2012). For instance, it was considered a taboo to kill animals without good reason

when one is pregnant: having sexual intercourse during pregnancy was considered wrong and failure to obey this could cause children to have disabilities when they were born and laughing at individuals with disabilities would cause disabilities in one's future offspring (Stone-MacDonald and Butera, 2012). The lack of knowledge about cerebral palsy evidenced in the current study reflects the lack of knowledge about disabilities as reported by the existing literature in the African populations. This suggests the need for increasing awareness and education to demystify and de-spiritualise cerebral palsy; for example disability campaigns and national campaigns to raise awareness

In the current study, societal opinion about the children with cerebral palsy featured strongly in the chaos narrative and this appeared to manifest itself through stigmatisation. The manifestation of stigma occurred in two ways; stigma from close neighbours and stigma from the community or the larger society. The stigma reported by study participants led to participants feeling that they have no control over others' opinions about the children. The occurrence of stigma in the current study was expected or anticipated prior to entering the study field due to its identification from the existing literature about families having children with cerebral palsy as reported in chapter 2 and through Erving Goffman's classical theory of stigma on the lives of people living with physical disabilities and others (Goffman, 2009, Carnevale, 2007). From Goffman's point of view, society places categories on people based on normative expectations; the "normals" are divided from the "deviants". He saw stigma as a deeply discrediting attribute, reducing in our minds the person that possesses a particular quality, "from a whole and usual person to a tainted discounted one" (Goffman 2009, p.3). According to Goffman therefore, people who are stigmatised can either be *discreditable* or *discredited*. By *discreditable*, he referred to those that have a stigmatizing characteristic but have not yet been discredited, chiefly because the stigmatizing characteristic is yet to be fully revealed. By using *discredited*, he related to those who are "socially judged and marginalised" due to having a stigmatizing quality (Carnevale, 2007, Goffman, 2009). When participants in this study constructed stigma, it appeared their narratives were congruent with Goffman's *discredited* category of stigma. This is so because it appeared family members or participants, were heavily distressed that the children's lives and conditions were devalued and discredited profoundly by society. Particularly striking was when the children were continually referred to by others as "not human" or "animals", and when participants

indicated that they were frequently pressured to terminate the lives of the children through rituals. There were some occasions where some participants were ostracised in the houses they lived as people did not want to associate with them due to the children with cerebral palsy. Experiencing stigma in public situations such as outings and gatherings was also common among participant narratives. It was during such outing and gatherings that the competence in handling children with cerebral palsy would be unfairly judged. Society further stigmatised participants by demonstrating abusive behaviours to the children with cerebral palsy. In the current study, stigma was a significant finding as it mostly caused chaotic reactions from participants, especially parents, and participants mostly felt that they have no control over others' opinions towards them and their children, further deepening the chaos narrative. It appeared then that the family members and their children in this study do not conform to acceptable social standards of normality as it appears they and the children are dismissed as fellow members of the community in which they live. There are further evidence or research works to support the stigma phenomenon that occurred in this study, which also serve as a reinforcement to the effect of stigma on family members having children with cerebral palsy. Families of children with cerebral palsy, mostly mothers, have been reported to face stigma, manifested mainly through negative societal attitudes (Alaee et al., 2015b, Baltor and Dupas, 2013b, Dehghan et al., 2015a, Huang et al., 2012b). Mothers have been reported to face stigma through the negative attitudes or ignorance of people who failed to understand and respect their children's condition. Such negative societal attitudes included staring, display of pitiful expressions, meddling and the propagation of faulty logic and beliefs. (Alaee et al., 2015b, Baltor and Dupas, 2013b). Stigma was significant as it made mothers feel marginalised, feeling reluctant at times to even come out and seek for proper medical support for their children (Huang et al., 2010b). In the wider literature on disabilities, stigma has been reported by parents which also reflect those experienced by the families of children with cerebral palsy. Parents of children with intellectual disabilities encounter negative public attitudes, reactions and behaviours which makes them feel stigmatised, perplexed and uncomfortable (Green, 2003). Some mothers of children with down syndrome have reported of being blamed by both family and community members as potential contributors to their children's disability through negligence (Green, 2003). Such stigmatisations have often elicited anger from parents (a finding which occurred in the current study) creating an emotional turmoil which they must

deal with. However, other parents cope with stigma by seeing the reactions of others as stemming from benign ignorance of the children's condition rather than malicious intent (Green, 2003). This reinforces the result evidence in this study when participants reported people expressed stigmatising attitudes to them and their children out of ignorance about cerebral palsy.

Other studies (Diver et al., 2013a, Nettleton et al., 2004, Reynolds and Vivat, 2006) that have used Frank narratives on ill persons' experiences have reported stigma occurring within the chaos narrative. Though these studies were conducted on ill people and not their family members, their findings on stigma reflect those evident in the narrative of family members and reinforce the authenticity of this finding in the current study, that stigma leads to a loss of control or the construction of the chaos narrative. In the illness narratives of individuals diagnosed with fibromyalgia syndrome, participants spoke of stigma in the chaos narrative and reported it as a challenge to their identity and perceptions of self (Diver et al., 2013a). Speaking of stigma, study subjects reported the triviality which people attached to their symptoms and the lack of visibility of the condition in the society which increased stigmatisation. Stigma had a significant effect on people with fibromyalgia syndrome as they were unable to transcend or control the negative perception of stigma on their identity and therefore found it difficult to come to terms with their identity (Diver et al., 2013a). In the narratives of art-making of people with chronic fatigue syndrome, participants constructing the chaos narrative spoke of stigma as a challenge to their self-image and stigma was significant in the lives of participants because they felt other people were misinterpreting their condition and participants were pessimistic that their social situation would ever change (Reynolds and Vivat, 2006). The illness was interpreted as a controlling force in their lives, causing the loss of many valued roles and activities. Participants felt that the social response to their condition, manifested in stigma, was difficult to control and undermined their self-image profoundly (Reynolds and Vivat, 2006). For those who lived with medically unexplained symptoms, the stigma attached to the condition was significant as it made them feel that their conditions were an embarrassment and shameful (Nettleton et al., 2004).

As this is the first study to adopt a multiple participant perspective to study the experiences of family members having children with cerebral palsy and also the first study to consider the use of Frank narratives focusing on family members of individuals living with the chronically ill, the findings of this study would combine with the findings of other studies that have mostly considered the experiences of the mother in the case of this study, and the experiences of the ill person as far as Frank's narratives is concerned, to establish that, parents, siblings and the extended family of the chronically ill may equally face stigmatisation and marginalisation by the society in which they live and that they are enduring a form of social suffering. This study has also contributed to the understanding of stigmatisation as a social issue that causes a loss of control among people living with children having cerebral palsy.

Frank described chaos stories as those that are chaotic due to their absence of a narrative order. According to him, the tellers of chaos do not tell the story of a "proper" life, because life as in a story, there is the expectation that one event must lead to another (Frank, 1995, Frank, 1998, Frank, 2013). He established that chaos stories are often told without a beginning, middle or an end and therefore referred to chaos as anti-narrative. This aspect of Frank's view on the chaos narrative was enacted in this study. It was evident that the chaos narrative moved in sequential order from diagnosis through the period when participants perceived both alternative and biomedical help had failed to the point where others' opinions about the children became rampant in participant reports. However, from this point, chaos progressed from being sequential into an anti-narrative as participants reported problems in no ordered sequence. They constructed chaos in the anti-narrative when they reported job problems, financial difficulties and burdens, loss of income, their inability to fulfil family responsibilities and anxiety over the children's condition. The chaos narrative portrayed no structure as participants jumped from one problematic issue to another.

Chaos as an anti-narrative, evident in the current study finding and supported by Frank's view, also reflects the characteristics of chaos presented by other authors who used Frank's illness narratives in studying ill person's narratives and their findings reinforces those of the current study. A study which purposed to understand parental experiences in having children with cancer in Canada, using Frank's illness narratives of Restitution, Chaos and Quest, reported that most participants told stories of chaos which interrupted the restitution narrative and this narrative did not appear to be in a

sequential order as it appeared to have no beginning, middle or an end (Bally et al., 2014). Likewise, breast cancer patients presented Chaos narratives about their conditions in which their stories did not flow well and participants interrupted themselves. Their speeches were found to be dominated by sentences that seemed to be jumping from one sub-topic to another (Thomas-MacLean, 2004). It was also observed in the chaos narratives of patients who had chronic obstructive pulmonary disease (COPD) that their chaos stories were stories of no beginning (Pinnock et al., 2011). It was impossible for patients to identify a beginning to the chaotic stories they told. It was reported that some participants identified some milestones and used them as a beginning to their chaos stories while a different beginning was also selected in subsequent accounts, portraying the fluidity and unstructured manner in which they told their chaos narrative (Pinnock et al., 2011). Their chaos stories in the study were found to be directionless, were impossible to be distinguishable from their life stories, lacked a clear beginning, had an unpredictable and unanticipated end (Pinnock et al., 2011).

The current study has demonstrated that from the point where the chaos stories of participants appeared not to follow any special sequence, their talks were filled with issues or problems that were presented as life difficulties. Most participants felt that their children would lose societal opportunities such as education, and this made participants, especially parents, demonstrate a sense of uncertainty towards their children's future. Some participants also recounted the loss of control over their own life plans and opportunities they had to let go due to the high dependency nature of the children. The chaos stories of participants also featured the financial burdens they experienced, which caused further enactment of the chaos narrative. Mothers had to terminate their jobs due to the highly dependent children and this had an adverse effect on the family finances as it contributed to financial stress. Fathers, who mostly had to shoulder the financial stress alone reported the pressure and the associated loss of control over the family finances, as they became sole breadwinners. Fathers became financially hard-pressed and sometimes had to uncomfortably ask for monetary assistance before being able to fend for their families. Relying on others for financial help was described as a challenge to self. In some families, these financial burdens threatened family breakdown as some fathers lived in fear of being cheated or divorced by their wives. The financial hardships also had a repercussion on siblings

as those siblings who were in school felt that they were losing control over their learning and education. The extended family also joined in the chaos narrative due to financial hardship, as they felt that they could not do anything to enable the parents transcend these financial hardships.

Losses, hardships, and socioeconomic issues, leading to a loss of control and the construction of the chaos narrative, as evidenced in this study, have also been presented by some studies (Diver et al., 2013a, Ezzy, 2000, Reynolds and Vivat, 2006, Vroman et al., 2009, Whitehead, 2006) that have used the narratives of Frank as an underpinning explanatory framework and these evidences further support or validate the findings in this study. In the narratives of patients diagnosed with Fibromyalgia syndrome (FMS), participants reported the losses they encountered and found it difficult coming to terms with such losses that the FMS brought in their lives (Diver et al., 2013a). Such losses encompassed those that occurred at home, at work and socialising. FMS appeared to represent the destruction of all that was good in their lives, which even included a desirable future. With time, their movement out of the chaos narrative appeared to be greatly impeded by a cascade of additional losses such as a loss of job resulting in the subsequent loss of income and which also presented fewer opportunities to socialise. These losses in turn impacted on their families, manifesting in the breakdown of relationships and communication (Diver et al., 2013a). The chaos narrative of individuals living with chronic fatigue syndrome (CFS) was marked by a loss of focus on everyday life notably among which were work and schooling (Whitehead, 2006). Study subjects described an empty present and a future that was desolate and at the same time contrasted it with a future that they had anticipated would promise much until CFS came to destroy it (Whitehead, 2006). Participants reported their life frustrations which comprised the loss of income, a loss of job or career plans and a loss of social contacts (Whitehead, 2006). In the narratives of art-making in chronic fatigue syndrome (CFS) which adopted a case study methodology in studying three cases, all three participants involved in the study constructed a chaos narrative (Reynolds and Vivat, 2006). In this study, it was reported some participants were unable to engage in paid work as they grew older because of CFS and with the exacerbation of CFS, an engagement in even sedentary activities became very difficult. Some participants also had to give up their jobs and professional career after the onset of CFS (Reynolds and Vivat, 2006). Furthermore, the most

common reason, as evidenced in the chaos narratives of people with low back pain (LBP), is the physical inability to engage activities of daily living and this was a strong sub-theme in the chaos narrative pertaining to the consequences of having low back pain (Vroman et al., 2009). The experience of LBP was exemplified by the suffering and disability which disrupted their lives. Life disruptions occurred to simple daily tasks such as dressing, housekeeping, driving, difficulties at work and in the engagement in sporting activities. Participants felt that their pain prevented them from living a life and doing activities that they anticipated was only possible without low back pain (Vroman et al., 2009). The chaos narrative of participants living with HIV also reported of losses which often included the abandonment of an occupational career as a result of HIV. The abandonment of career was concomitantly associated with increased social isolation due to being unable to finance social outings and also as a result of losing social contacts at the workplace (Ezzy, 2000).

Losses and other dire impacts associated with having children with cerebral palsy have also been described and presented in other qualitative research studies (Baltor and Dupas, 2013b, Dantas et al., 2012b, Dehghan et al., 2015a, Fernández-Alcántara et al., 2013, Fernández-Alcántara et al., 2015, Milbrath et al., 2008b, Zuurmond et al., 2015) and these existing evidence offer a further validation for the findings in this study. It has been reported that cerebral palsy has a great impact on the family by causing the family to reorganise itself to find ways of meeting the needs of the special child. Caring for the child is mostly regarded as a priority and the time allocated for the child care most often causes an interference with the labour activity of at least one of the family members and changes or impacts in the lives of parents, especially mothers, have been shown as time demands, labour, economic situations and a negative effect on relationships (Baltor and Dupas, 2013b, Fernández-Alcántara et al., 2013, Zuurmond et al., 2015). It is also known that having a child with cerebral palsy has a significant impact on mothers as it mostly limits their ability to socially and professionally interact with people outside their home environment due to the dependent nature of their children's condition (Dehghan et al., 2015a, Milbrath et al., 2008b). Though the findings of the existing literature validates the findings of the current study with regards to impact of cerebral palsy on the family, the current study has expanded the qualitative literature on the impact of cerebral palsy, through the employment of different heterogeneous groups in the family as the existing literature

has mostly focused on mothers experiences. The current literature has demonstrated how the personal impact of cerebral palsy may play out for the different members of the family. This study has established that it is likely for mothers to lose their jobs due to the dependent nature of the child while fathers are likely to uncomfortably shoulder most of the financial responsibilities in the family when mothers are out of work. The inability of the mothers to work increases the financial burdens in the family and this may threaten family relationships. Children in the family may suffer, especially with the tuition for their education as a result of the crippled family finances. The extended family on the other hand, may demonstrate a loss of control as they express their incapacity to help with family finances.

9.6 Quest

In this study, quest was constructed when participants came to the point in their experiences where they made sense of the cerebral palsy experience. Quest in this study was influenced by the *Auto-mythology* and the *Manifesto and Memoir was not constructed*. In the quest stories of parents whose children had childhood cancer, the quest narrative was prominent in the accounts of only a few parents and quest stories were not as common as the restitution and chaos (Bally et al., 2014). This finding contrasts with the current study in which all parents constructed and dominated the quest narrative. Quest narratives may not have been common in parents having children with childhood cancer as the children in the study were reported to be still in the early phases of cancer treatment compared to the current study in which participants had lived with the children for more than five years and had explored both biomedical and alternative treatment through these years with their children. This could also be explained in part by the possibility of cure for childhood cancers. In those with stroke, religious beliefs also helped in coming to terms with the impact of the stroke, leading to the construction of the quest narrative, (France et al., 2013), a finding which reinforces the religious beliefs evident in the current study which informed part of the quest narrative. However, this study failed to mention explicitly what religious beliefs there were that influenced the quest narratives of men and women with stroke. Hence, the findings of the quest narrative with regards to the automythology, which was influenced by participants' belief in a higher power, are unique, as this is the first study among those using Frank's narratives as their explanatory model, to explicitly present quest findings by participants informed by religious beliefs. When participants

in the current study constructed the quest narrative, the quest auto-mythology, to be precise, it was mainly influenced by their religious beliefs, which they used to romanticise that cerebral palsy was both the will of God and a test from God. Participants believed that having a child with cerebral palsy was the will of God but this was arrived at after realising that all avenues they had explored, expecting that cure could emanate from these avenues, had failed to fulfil their expectations. Participants believed that it was the will of God for cerebral palsy to happen to their children, and they appeared to have no other credible explanation and further attributed what the future holds for the child, to the will of God. Participants also believed that cerebral palsy was a test from God, however, this was the construct of parents only. Parents' believed that their children having cerebral palsy was a deliberate action from God to test the strength of their religious faith. They seemed to stress that an unflinching faith in God, despite facing the cerebral palsy test, would mean that one has a strong faith in God and they would sometimes justify this conviction by quoting biblical texts.

For participants in the current study, it appeared that the religious meaning they attached to having a child with cerebral palsy was also characterized by the concept of fatalism (Taylor, 1962). Fatalism reflects the thinking that individuals don't have the capacity to determine what happens in this life. Taylor (1962), in his concept of fatalism, stressed that individuals might get to thinking about fatalism in different ways but their ideas of fatalism are likely to be derived from theology or natural laws. If the individual believes that God is really all-knowing and all-powerful, then he might resort to the supposition that God had arranged everything to happen just as it was going to be. In this study, participants believed, that cerebral palsy was God's arrangement, and it was deemed to happen to their children, just the way it happened, demonstrating a fatalistic belief. Existing literature shows some studies that have considered the effect of religion or religious beliefs on health, in conditions such as cancer, heart disease, kidney disease, HIV/AIDs, Lung disease, sickle cell, diabetes, cystic fibrosis, and amyotrophic lateral sclerosis (Ai et al., 1998, Avants et al., 2001, Cooper-Effa et al., 2001, Matthees et al., 2001, Murphy et al., 2000, Samuel-Hodge et al., 2000, Schnoll et al., 2000, Stern et al., 1992, Tix and Frazier, 1998). These studies have reported that persons facing life-threatening conditions may resort to religious beliefs as a significant resource, to help them come to terms with and accept their conditions.

It has also been reported that religion may be equally an important coping mechanism for people living with chronic disabilities such as traumatic stroke, arthritis, epilepsy, brain and spinal cord injuries (Johnstone et al., 2007). These individuals are expected to live for a very long time, even for years or decades and may employ religious beliefs to help them in coping with their disability, construct new meanings to their lives based on their disabilities and this may also help them establish new goals in life (Johnstone et al., 2007). Religious coping has been shown to be significant in chronic conditions as it has been shown to add unique power in predicting positive adjustments for persons with disabilities (Pargament et al., 1990). There has been considerable research on how individuals cope with disabilities through the use of religious or spiritual coping strategies (Johnstone et al., 2007, Koenig, 2002). The faith in a higher power, for most religious individuals, has been reported to be sufficient enough to deal or cope with their disability and that for many persons with illness, who may seem helpless and not in control of their conditions, religion has been shown to provide them with some indirect form of control (Johnstone et al., 2007, Koenig, 2002). It has also been reported that religious coping can be passive, in which individuals turn their problems to God (as evidenced in the current study) or active, in which there is increase in the performance of prayers and other religious rituals (also evident in the current study) and for some individuals, religious coping can be personal (appealing to God for intervention) or interpersonal (asking for the support of clergy and congregation in prayers) (Johnstone et al., 2007, Koenig, 2002, Pargament et al., 1990). Religious coping has therefore been categorised into three strategies: a) *spiritual religious support* (the individuals feel or perceive that a higher power, God, supports them, b) *Clergy and congregational support* (individuals ask for fellow religious members and religious leaders for support) and c) *Benevolent religious reframing* (this is a cognitive reframing in which negative events are attributed to the will of God or to Karma in oriental religions (Pargament et al., 1990). Research has also suggested that religious coping are often used by persons of low income background, older persons, Africans, African Americans, females, people with less formal education, widows and widowers, fundamentalists and church goers (Ai et al., 1998, Avants et al., 2001, Johnstone et al., 2007, Koenig, 2002, Pargament et al., 1990, Schnoll et al., 2000). Therefore, the religious findings in the quest narrative evident in the current study could also mean that participants were trying to cope with the long-term nature of cerebral palsy by attaching a religious meaning or sense to the

experience. In the current study, passive religious coping was evident as participants talked of leaving the children's condition in the hands of God and benevolent religious reframing was demonstrated when participants attributed cerebral palsy to the will of God. This may demand a duty, on the part of healthcare professionals and researchers, especially those operating in underdeveloped settings, in paying attention to religion stories when listening to illness narratives, as religion and spirituality seem to play a central role and appears to be inevitable in the lives of most individuals living in underdeveloped and even in some developed settings. In listening to illness narratives, it would be necessary for healthcare professionals operating in underdeveloped settings to determine the religious affiliation, religious beliefs and associated practices of their patients and their family members, and to find out which of their clients may benefit from religious coping strategies.

The quest manifesto, the least gentle of the three quest types, was enacted by participants in the current study. The manifesto treats the truths that have been learned from the illness experience as prophetic as it carries a call or demand for social change. Participants in the current study enacted the quest manifesto when they called for social change with regards to the recognition of the rights of children with cerebral palsy and their families, cerebral palsy awareness, attitudinal change in society towards children with cerebral palsy and their families, equalising societal opportunities, factoring cerebral palsy issues into government policies and government interventions for families having children with cerebral palsy. The call for societal change was largely fuelled by how they have observed through the various mass media, how persons with disabilities and their families in the West, live fulfilling, well meaningful lives and accorded their due rights. They felt that how persons with disabilities and their families are treated in the west could be replicated in the Ghanaian society and therefore urged the government and society in this regard.

The enactment of the quest manifesto is unique to the current study as all the 11 studies that have been conducted in light of Arthur Frank's narratives have not reported the quest manifesto in their quest findings. This could be explained by the contextual differences between the current study and the rest of the existing literature on Frank's narratives. The existing literature on Frank's narratives have come from developed contexts where disability issues have undergone a total revolution and have been far addressed as compared to the developing context where this study was

conducted. In well-developed contexts, public policies have seized political and institutional structures to solve disability issues. Furthermore, with the advent of the social model of disability in the West, user-led disability organizations have prompted policy and institutional reconfigurations that have largely created opportunities and great new expectations for persons with disabilities (Shah and Priestley, 2011). However, disability issues with regards to social inclusion and societal change for persons with disability and their family members have woefully been unaddressed in developing countries. It is not surprising then that when participants in this study called for a social change within the quest narrative, they largely referred to what is described as change within the social model of disability. The social model of disability argues that people are being disabled not by their impairments but through the disabling barriers that society constructs (Oliver, 2013). Therefore, the social model of disability aims to identify and eradicate the barriers that are put up by society against persons with disability and their families. Through the social model, barriers to the environment, employment systems, transportation systems, educational systems and other institutionalised systems in especially western countries have been eradicated or mitigated to embrace the idea of social inclusion for PWDs and their family members (Oliver, 2013) but this cannot be said for underdeveloped contexts. While societal inclusion is an essential component of democratic societies, the concept is only accepted in discourse and hardly does it become a reality in developing countries (García-Huidobro and Corvalán, 2009). Descriptive data from the *World report on disability*, depict that persons with disabilities in developing countries are disadvantaged as far as educational attainment and labour market outcomes are concerned and face barriers in accessing healthcare (WHO, 2011). A large number of children with disabilities in many developing countries are still being denied access to inclusive education (Yu et al., 2011, Sharma et al., 2013). Therefore, the quest manifesto evident in the current study affords family members the opportunity and voice to call for social change to their children's circumstances as well as theirs, a finding consistent with Frank's views on the quest manifesto. The findings of this study has therefore contributed to the existing research on how society still continues to contribute to disability in underdeveloped contexts. However, the findings of this current study, as expressed through the quest manifesto, demonstrates that family members no longer want to endure the social exclusion that they and the children with

cerebral palsy encounter. They have expressed the need for social change, a change that would bring inclusive social opportunities and eschew exclusion.

9.7 Implications for clinical practice

The findings from this thesis have revealed that restitution, chaos and quest narrative types are present in the experiences of family members who live with children with cerebral palsy and that the understandings from their narratives are contextualised and while some correspond to the existing literature on Frank's (1995) narrative typologies, others are unique. This would mean that health professionals dealing with family members living with children having cerebral palsy could attend to their stories in an opened and focused manner in order to honour and validate their stories as well as their experiences. Frank theorised that illness is a disruption to the ill person's life and those who attend to the ill person are also impacted by the illness experience and that through the telling of stories, some semblance of coherence could be found and this coherence plays a significant role in facilitating healing or putting self-back together again (Frank, 1995, Frank, 1998, Frank, 2013). Therefore, there could be a positive enhancement in listening to the stories of family members having children with cerebral palsy and other chronic illness if there is a simple method or framework to guide listening, such as the one provided by Frank in his narrative typologies of restitution, chaos and quest. The findings of the current study have made it evident that the development of strategic approaches in addressing the experiences of family members is very important. Therefore, health professionals could establish a safe environment for family members having children with cerebral palsy to share their stories. Family members would feel respected as they are viewed as owners of their own stories and interpersonal relationship between professionals and family members would be enhanced. Furthermore, the recognition of such stories by health professionals could lead to more focused assessments, care and interventions for ill persons and their families as there is the evidence that when family members and patients are recognised as active participants in healthcare, the experience of care and health outcomes become improved substantially (Smith et al., 2013). Through using Frank's narrative typologies as listening tools for cerebral palsy experiences, family members who may tell the restitution stories could be supported to come to the realisation that cerebral palsy cannot be cured but rather managed. Health professionals could then lead them to understand and practice the various ways of

managing cerebral palsy and in preparing well for the uncertain future of the children. Family members who may tell the chaos narrative could be offered an assistance and encouragement and counselled to understand that chaos will not last forever and will retreat ultimately. Healthcare professionals, especially those in developing settings, could also be encouraged to monitor family members who may be experiencing relationship breakdown and may be going through severe chaotic emotions as a result of having children with cerebral palsy. Health professionals could also support in mitigating the everyday hardships as a result of having children with cerebral palsy, through helping them to seek for appropriate social interventions. Family members could also be helped in coping with culturally sensitive issues such as stigma, marginalisation and ostracism which mostly leads to a loss of control. Family members who may express their experiences through the quest narrative could also be supported to come to terms with cerebral palsy and in their pursuit of finding meaning and purpose to the cerebral palsy experience. Especially could they be supported in coping with the children's condition. For family members who may want a social change through expressing the quest manifesto, health professionals could back them in letting their voices heard in society and to also fight for policy interventions.

9.8 Social and policy implications

In line with the 2030 Agenda for Sustainable Development, which ensures that all countries would achieve sustainable development goals and that no persons are left behind, many countries around the world, have introduced disability laws and acts which ensure that persons with disability are included in the sustainable development agenda (Morrissey, 2012, Grammenos, 2013). These laws and acts contribute to progress towards the implementation of the International United Nations' Convention on the Rights of Persons with Disabilities (CRPD) (Morrissey, 2012, Grammenos, 2013). For example, laws which guarantee equal access to education, employment, public buildings, and social activities have been put in place in America and Europe (Grammenos, 2013, Morrissey, 2012). National, commercial, and foundational funding have also supported research in the field of disability and rehabilitation including the development of technologies that serve as a support for mobility, cognitive and sensory functions for persons with disabilities (Grammenos, 2013, Morrissey, 2012). Early interventional programmes have also been planned to identify and treat developmental issues or disorders in young children, with empirical research seeking

to identify causes and new treatments for common disorders (Grammenos, 2013, Morrissey, 2012). The findings of this study suggest that it is important to consider the needs of children with CP and their families in Ghana who may not be getting the support they need. Therefore, apart from enhancing the understanding of the experiences of family members living with cerebral palsy through the listening tools of restitution, chaos and quest, findings from this thesis also point to the need for improving cerebral palsy and other disability experiences for family members in Ghana and in other developing settings that may present similar sociocultural backgrounds. Considering the fact that living with children with cerebral palsy have several impact outcomes or effects which are likely to remain with family members in the long term, approaches for improving the experiences of family members living with children with cerebral palsy and prospective family members who may have these children in future should be of high interest to policymakers both national and local, non-governmental organisations, national and international researchers and other related organised bodies who may have interest in cerebral palsy issues. The findings of the current study have important recommendations to inform future policy and education in Ghana.

- There should be an emphasis on the need for cerebral palsy awareness programmes in future policies as it appears its knowledge among family members and the Ghanaian society is lacking. In enhancing cerebral palsy awareness programmes, there should be the involvement of various stakeholders such as primary stakeholders (family members and the children with CP), local leaders, religious leaders, leaders in government, and if possible, international representatives for cerebral palsy.
- Social intervention policies that aim to mitigate the personal impact of cerebral palsy such as financial hardships or loss of economic power, loss of jobs leading to loss of income and inability to fulfil family responsibilities, should also be considered or existing ones must be improved and made effective.
- It is also important that government policies in Ghana concerning the issue of societal inclusion for all with regards to access to education, healthcare, transportation and employment for persons with disabilities are reinforced. This would decrease the high dependency of these children on family members

- There could also be the formation of self-help groups (SHGs) to address the problems of family members and to also empower them. Self-help groups have been described in literature as a very essential human resource and social utility (Finn, 1999, Katz, 1992). SHGs have become a means through which people with mutual problems attempt to gain control over life circumstances that affect their lives (Finn, 1999). They are based on principles such as empowerment, shared responsibility, holistic approach to sociocultural and socioeconomic needs and inclusion (Finn, 1999, Schopler and Galinsky, 1993, Segal et al., 1993). There has been an exponential growth in SHGs in the healthcare arena and memberships have included people living with chronic conditions and their families, people who require rehabilitation in the long-term, people who experience bereavement and terminal illness and individuals recovering from various health risk addictions (Finn, 1999, Riessman and Carroll, 1995). There are several factors that have prompted the formation and upsurge of SHGs and such factors reflect many of those encountered in the current study. These consist of inadequate support for chronic conditions within the medical system, increasing distrust of health professionals, growing interest in alternative medicine, a rise in consumer consciousness, and rising healthcare costs (Finn, 1999, Riessman and Carroll, 1995). Research has evidenced that participation in SHGs have had positive outcomes as self-help groups have been able to successfully provide services such as: sharing of information, resources and ideas, engaging in effective dialogues to find solutions to social issues, providing mutual support in hard times, engaging in problem-solving, overcoming stigma and isolation, putting forward demands for change, developing social networks and serving as sources of inspirations and hope (Finn, 1999). It would, therefore, be appropriate for families having children with cerebral palsy to form self-help groups and utilise these groups as a form of social support.

9.9 Recommendations for further research

- I. As this is the first study to consider the experiences of family members surrounding the chronically ill child with the use of Frank's narratives, more research is needed to validate the repeatability of these findings in other settings

- II. The current research has focused on the experiences of those family members living with children with cerebral palsy from 5 years and above and has identified the presence of Frank's narratives of restitution, chaos, and quest. Further research may be needed to explore the narratives of family members living with children below 5 years of age and family members living with adults, with chronic illness or disability, to find out if their narratives would be enacted, differ or remain the same.
- III. Further research may also be needed to examine the issue of stigma associated with families having children with disabilities in more depth. Such empirical knowledge could be able to help in developing appropriate, responsive and effective strategies aimed at reducing or even eradicating stigma, marginalisation and discrimination that families having children with cerebral palsy or other disabilities encounter in their everyday endeavours

9.10 Strengths and limitations of the study

9.10.1 Limitations

The limitations of a study represent the systematic biases that were beyond the control of the researcher and which could affect the results of the study inappropriately.

In this research, I have no way of knowing, empirically, to what extent the results would be similar or different in another study setting given the small sample size and the specific nature of the study. Nonetheless, the study findings provide a novel step into understanding the illness narratives of family members living with children having cerebral palsy in a low-income setting and from these findings, further research involving larger study samples may draw in order to test some of the propositions made in this study.

Furthermore, this study may demonstrate a potential for selection bias as the first step to gain access to participants was in a healthcare institution. This meant that only the family members of mostly mothers who came to the selected regional hospital with their children for routine physiotherapy treatment were included in the study. Furthermore, since the sampling technique employed in this research was not random but purposeful, it was exclusive of family members who were accessing physiotherapy

treatment from district hospitals as well as private hospitals. Further research may therefore be needed which may incorporate participants from the various hospital levels (regional, district and private).

Similarly, there could be a potential for the influence of power in this study though I endeavoured to mitigate this by establishing rapport and relating well with study participants. Nevertheless, some participants might have felt that as a health professional, I was an insider, and therefore disclosed only the information they felt comfortable with.

Furthermore, my own professional background as a person who works with persons with disability and their families and who wanted to elucidate their experiences might have influenced the way I interpreted study findings though I endeavoured to allow my interpretations stay close to the data as far as possible.

9.10.2 Strengths

To the best of my knowledge, this is the first study which has employed Frank's illness narrative typologies as a framework to study the experiences of persons around the chronically ill child by employing multiple participant perspectives from the family and have found the existence of dominant typologies of restitution, Chaos and Quest in their narratives. Existing literature portrays that the use of this framework has mostly centred on the experiences of the ill person only. Out of the two papers that even endeavoured to look into the experiences of those surrounding the chronically ill, one identified chaos stories only and the condition studied was an adult chronic condition (Pinnock et al., 2011). The other one identified dominant restitution and chaos stories but quest was less dominant (Bally et al., 2014). Even for Bally et.al (2014), their study was biased towards mothers and the condition studied, childhood cancer was not found to be chronic due to advances in medicine that makes this condition curable. This research, therefore, provides a novel insight into the illness narrative of family members living with chronically ill children as it has identified the presence of dominant restitution, chaos and quest in participant narratives.

In addition, it is also the first study to elucidate the experience of living with children with cerebral palsy in the family using Frank's narrative typologies as listening tools to further enhance the understanding of cerebral palsy stories. This would also be the

first study to have been conducted in a less developed context that has identified the presence of Frank's narratives.

Furthermore, this research adopted the pragmatist approach of constructing knowledge and the generic qualitative methodology which allowed the generation of key concepts through an inductive approach before applying the interpretive framework. In this way, study outcomes were grounded in data and the framework also provided an in-depth explanation of findings which have helped improve the understanding of living with a child having cerebral palsy in the family.

Even though the study employed a small sample size, sampling was triangulated by recruiting different participant groups within the family (mothers, fathers, siblings and extended family). Although the findings would prove that the experiences of living with a child with cerebral palsy were similar based on participant views, however, the results would provide more reliable evidence compared with the existing literature which has mostly relied on the experiences of the mother. Last but not the least, the research process has included constructive critiques from supervisors who are experienced researchers as well as an internal reviewer and this increases the authenticity and trustworthiness of the study findings.

9.11 Reflexivity: The effect of the research on the researcher

It is suggested that the feelings of the field researcher does "not only affect the research but it also becomes part of the research process itself" (Kleinman, 1991) and much has been written about the researcher as part of the field being studied (Schutz, 1994)

During the research process, I found myself ruminating or thinking about the ways in which my own experiences and philosophies have shaped the research but I also kept thinking about how the research touched, affected or possibly transformed me as a professional. Under this section, I will present some of these reflections about the research process. What I discovered was how the views of participants impacted on me and encouraged me to find more about these participants in order to let their plight be known to stakeholders. For example, when I heard about how participants reported cerebral palsy as mysterious, spiritual and strange, my own experiences from childhood narrated to me by my parents occurred to me and somehow made me

believe that what participants were reporting could be true. However, my professional knowledge about cerebral palsy, its causes and longterm nature, conflicted with this thought. It is a very popular story in both my nuclear and extended family, that I am a unique child to my parents and the reason I was christened Emmanuel (the meaning of Emmanuel is "God with us"). I was told that during my conception, there was a witch doctor in my family who had already told my mother that she was not destined to give birth to boys in this life. True to the words of the witch doctor, according to my mum, every girl child she gave birth to, before me, survived but every boy child, born before me, died mysteriously. Therefore, when my mother conceived me, this same witch doctor reiterated to my mother that she must abort me, else I would die after birth or the two of us would die mysteriously during delivery. Mum said she continued in prayers until the day of delivery. According, to my mum, she delivered me safely, with no birth complications but another interesting but strange incident occurred that same day and in the hour when I was delivered. My mum's sister, who was also pregnant with a baby boy and was due to deliver a week after my mum's delivery, died mysteriously together with the child in her womb, that same day and hour, to the shock of the entire family members. My mum said that about some weeks later, some strange person met and told her that her pregnant sister and her child's soul had been exchanged spiritually for my mother's soul and mine, the reason we didn't die. That person explained to my mum that there was some mysterious spirit in our family that were always using the boys my mum gave birth to for rituals, but when my mum became a believer in God, that spirit couldn't overpower my mum and me, due to God's protection; therefore that spirit needed to kill my mum's sister and her unborn child as a replacement.

When participants narrated that their children's condition was surrounded by mystery and spiritualism, their stories made me recall this popular story in my family and aligned it with what they were saying. They believed their children were unique and were going to be great people in the future; to prevent this from being fulfilled, some evil spirits or evil people had cast cerebral palsy on their children. I identified with them because of my own story. I could also understand their hope for restitution and that they were praying to God for a cure; part of me wished that God would indeed heal their children. However my professional identity, conflicted with this wish; I am aware through scientific research and explanations that this condition has no cure in the

biomedical world and that mystery and superstition are ruled out in as far as the causes of cerebral palsy are concerned. I experienced a conflict of thoughts whenever the issue of mystery, superstition, spiritualism and belief in God for cure came up in the interviews. Vehemently did the story of my life and their belief in mystery and spiritualism challenged my scientific knowledge. As I continued to encounter more participants who shared similar thoughts about mystery and superstition as the cause of cerebral palsy, I was conscious that whilst scientific knowledge about cerebral palsy has proven to be true over the years I would not condemn mystery and spirituality as proposed by participants.

There were also a number of times during data collection when I felt some empathy for the participants and more so when they narrated the personal impact of cerebral palsy on their lives. I felt for them when they reported a loss of control over their lives and their family and especially those who reported a family breakdown due to financial hardships. For example the narrative of Abraham, who feared losing his wife because of not being able to provide for his family as a result of the financial hardships he faced due to having a child with cerebral palsy in the family. The wife of Abraham had stopped working for a long time to take care of their child with cerebral palsy and this meant that Abraham was the only person fending for the family. This alone had become an immense task for Abraham as his job was not lucrative enough to cater for the whole family. According to Abraham, the daily needs of his wife and children were not met and he feared she had started having affairs with other men. I could see the eyes of Abraham being wet with tears and the tone of his voice changed and he was shaking as he talked about this with me.

I could identify somehow with Abraham's experiences of the fear of losing his wife; during my first year studying for my PhD, my girlfriend of nearly 10 years who I had planned to marry broke up with me, and within 6 months had married another person following my relocation to England. This was a devastating and heartbreaking experience and the emotions associated with it were unbearable: I found it hard combining this with the rigorous academic work in the first year. I felt I needed emotional and professional help but that this would delay the process of my confirmation review. I kept this away from my supervisors, fearing that I would be asked to take some time off my studies, something I was not prepared to do. After an interview with Abraham, I shared my experience with him and encouraged him to keep

on and hope for better days. I went to the house and reflected on his interview and the memories of those heartbreaking moments refreshed in my mind and my eyes were full of tears as I reflected:

“Abraham has revealed to me how his relationship with his wife has gone sour due to financial hardships which started sometime after her wife had to stop working and take care of the child. He fears that his wife may leave him soon. I understood the pains, the fears and tears in his eyes when he narrated this to me. Even when my long-time girlfriend left me and got married to a different man, it was a devastating experience and I felt like my whole world was coming to an end. So if a girlfriend could make me feel this way, then a wife of many years whom he has children with, would be more devastating and disastrous for Abraham should this woman decide to leave. I pray this woman stays with her husband. It is evident from his interview that he may need a financial intervention else he risks losing his marriage.”

In order to ensure the narratives of the participants are heard beyond this thesis I will disseminate them within research publications but also with health care providers in Ghana.

9.12 CONCLUSIONS

This final chapter has presented an interpretation of the findings of this study, situating the findings into existing literature that has employed Frank’s narratives as well as the wider literature on cerebral palsy. These interpretations have provided evidence of how the research question has been answered, how existing studies reinforce and reflect the findings in this study and also the findings that are unique to this study only. This study has supported evidence of Frank’s narratives in illness stories and has demonstrated further evidence for this model’s robustness in making the stories about chronic conditions meaningful. The use of Frank’s narratives in this study has provided a unique structure for listening to and understanding the experiences of living with children having cerebral palsy in the family by employing multiple participant perspectives. Without Frank’s listening tools of restitution, chaos and quest, the complexity and variability of family members’ experiences could have been underestimated, as this has been the case in the existing studies on cerebral palsy

that focused on thematic analysis only. This study has highlighted that clinicians or health workers could use Frank's tools to listen to the stories of illness more effectively to make informed decisions in helping or supporting family members of the ill person. Implications for social policies and interventions that could raise cerebral palsy awareness and address the needs of family members living with these children, and recommendations for further research have also been presented.

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APPENDICES

Appendix 1: Ethical approval letter from study site



KWAME NKURUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF MEDICAL SCIENCES
DEPARTMENT OF CHILD HEALTH

To Whom it May Concern 09/09/2016

Dear Sir,

Permission to Conduct Research in the Department of Child Health

This is to confirm that I have lectured and supervised Mr. Emmanuel Asante during his MSc. Programme in Disability, Rehabilitation and Development in the Centre for Disability and Rehabilitation studies, School of Medical Sciences in KNUST, Kumasi-Ghana.

He did attachments in the Department of Child Health, Physiotherapy and others in the Komfo Anokye Teaching Hospital where he gained sufficient experience in cerebral palsy. He is familiar with the protocols of this hospital and known personally to some of the staff in these units.

I have no reservations in granting him permission to undertake his research the Neurology Unit of the Department.

Best regards


Dr. Joslin Dogbe
Head, Paediatric Neurology
KATH/KNUST
Kumasi, Ghana

Private Mail Bag, University Post Office, Kumasi, Ghana. Phone: 233 03220 36751 Fax: 233 3220 60302
website: www.knust.edu.gh

Appendix 2: Consent Form



Title of Study: Experiences of family members living with Children with cerebral palsy in Ghana- A Qualitative Study

Name of Researcher: Emmanuel Asante (PhD Student), Professor Joanne Lymn, Dr. Claire Diver

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet version numberdated..... for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I understand that the interview will be audio recorded and that anonymous direct quotes from the interview may be used in the study reports.

4. I understand that all data will be anonymous and confidential with the exception of information being revealed during the interview which is of concern and may need reporting i.e. potential risks to another person or to myself

5. I understand that information about me recorded during the study will be kept in a secure database. If the data is transferred it will be made anonymous. Data will be kept for 7 years after the study has ended and then securely destroyed.

6. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person taking consent Date Signature

2 copies: 1 for participant, 1 for the project notes.

Appendix3: Participant Information Sheet

Title of Study: Experiences of family members living with children diagnosed with cerebral palsy

Name of Researcher(s): Emmanuel Asante, Professor Joanne Lymn, Dr. Claire Diver

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

This study wants to find out what it is like to be living in a family with a Child with Cerebral Palsy (CP) in the family

Why have I been invited?

You are being invited to take part because you have a child, aged 6-17 years, with cerebral palsy whom you live with.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you don't want to take part, it is not compulsory

What will happen to me if I take part?

If you wish to take part you will be asked to take part in a discussion with the researcher about what it is like to live in a family with a child with cerebral palsy. The discussion will take part somewhere that you choose. For example, in your home, at the hospital or in a café. They will ask you some questions and you will have the opportunity to tell them what you think is important about this .This will take around 1-2 hours and will

be audio taped. This will then be typed up and analysed for common themes in what people have said.

Expenses and payments

You will not be paid to take part in the study

What are the possible disadvantages and risks of taking part?

There are no expected risks in taking part of this study, however, you may be asked to talk about things that might be upsetting. It is your choice as to whether you talk about these sorts of things or not.

What are the possible benefits of taking part?

The study is unlikely to benefit you directly but the information we get from this study will help us to understand what it is like to live with a Child with CP. It is hoped that this information might be used in the future to support families living with children with CP and their carers.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled with confidence. If you join the study, the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty. All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. You will not be named in any of the study findings or anything that is written up e.g. PhD thesis

What will happen if I don't want to carry on with the study?

Taking part in this study is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?

Results from this research will be written up in an academic thesis. They may also be used in local and national publications including academic journals, and at events that are used to inform service development

Who is organising and funding the research?

This research is being conducted as part of a PhD. This is being funded by the Vice Chancellor's scholarship

Who has reviewed the study?

This study has been reviewed and given favourable opinion by University of Nottingham and Komfo Anokye Teaching Hospital Research and Ethics Committee

Researchers Name and contact Details

Emmanuel Asante (PhD Student)

Ghana contact: +233542573769

United Kingdom contact and address:

00447553185747

19 Lonsdale Road

NG7 3DU

Email: Emmanuel.Asante@nottingham.ac.uk

Professor Joanne Lymn

Dean of School of Health Sciences

Professor of Healthcare Education

Director of Learning & Teaching

University of Nottingham

Email: joanne.lymn@nottingham.ac.uk

Dr. Claire Diver

Assistant Professor, Physiotherapy

Director MA Research Methods (Health)

Email: claire.diver@nottingham.ac.uk

Appendix4: Information sheet for Physiotherapists



You are being provided with this information sheet concerning this research as we hope you will be able to assist us to recruit participants for the study.

Study Title: Experiences of family members living with children with Cerebral Palsy in Ghana- A generic Qualitative Study

Background

This study aims to explore the experiences of family members living with Children with CP and to raise stakeholder awareness about these families and their Children with CP. This research is being carried out by Emmanuel Asante, a full time PhD student at the University of Nottingham, United Kingdom with the help of Professor Joanne Lymn and Doctor Claire Diver as his supervisory team.

Who can take part?

We are looking for families having children with cerebral palsy from ages of 6-17 years. We would like you to tell any family member above age 17 years (this is likely to be the child's mother in the first instance) who brings the child to the hospital about the study and find out if they are interested in taking part.

What do I do if I identify a potential study subject?

On the identification of a potential study participant, please tell them about the study and ask if it's okay for us to contact them to explain the study further. Give them the participant information sheet to carefully read through and take their contact details, and how they would be preferred to be contacted. Afterwards, we will call these people to talk more about the study, see them and consent them to the study. We will ask them to talk to other members in the family and see if they would like to take part.

What will happen to the people who take part?

Participants will be asked to meet for an interview with the researcher at a place and time convenient for them. They will be asked to talk about their experiences of living

with a child with CP. An interview guide will be used that includes some questions of interest to the researcher. However, the participants will also be allowed to talk about things that they think are important that might not have been considered. They can stop the interview or withdraw from the research at any time.

Researchers Name and contact Details

Emmanuel Asante (PhD Student)

Ghana contact: +233542573769

United Kingdom contact and address:

00447553185747

19 Lonsdale Road

NG7 3DU

Email: Emmanuel.Asante@nottingham.ac.uk

Professor Joanne Lymn

Dean of School of Health Sciences

Professor of Healthcare Education

Director of Learning & Teaching

University of Nottingham

Email: joanne.lymn@nottingham.ac.uk

Dr. Claire Diver

Assistant Professor, Physiotherapy

Director MA Research Methods (Health)

Research Officer ACPOMIT

Email: claire.diver@nottingham.ac.uk

Appendix 5: Study Poster

THE EXPERIENCES OF FAMILY MEMBERS LIVING WITH CHILDREN DIAGNOSED WITH CEREBRAL PALSY

We are looking for volunteers to take part in this study

- | | | |
|--|---------------------------------------|--|
| 1. DO YOU LIVE WITH A CHILD WITH CEREBRAL PALSY WHO IS BETWEEN 5-17 YEARS? | 2. ARE YOU MORE THAN 17 YEARS OF AGE? | 3. IF YES, THEN YOU ARE WELCOME TO BE PART OF THIS STUDY |
|--|---------------------------------------|--|



For more information, please speak to any of the physiotherapists around or contact the researcher using the contact details below the leaflet. Thank you

Contact Details of Researcher
Emmanuel Asante (PhD Student)
University of Nottingham
Contact numbers : +233542573769/00447519581210
E-mail : Emmanuel.Asante@Nottingham.ac.uk

Appendix 6: Interview guide

Demographic Characteristics

Age of child:

Severity of the child's disability:

Age of family member:

Occupation of family member:

Questions

1. Tell me about when 'insert name of child' was diagnosed with cerebral palsy.

Prompts

- How old was he/she?
- Who told you about this?
- How did it make you feel?
- Had you thought something was wrong previously?
- Can you tell me what you did next?
- What did this mean to you and your family?

2. Tell me about what it's like living with 'insert name of child'

Prompts

- On a day to day basis what does this mean for you/other family members
- How does it make you feel?
- Have your thoughts changed since they were diagnosed?

3. Tell me about your relationship with the child?

Prompts

- How do you feel about this?
- What is significant about this to you?
- How does this compare with the relationships you have with any other children you have?

4. How does living with 'insert name of child' affect your daily life

Prompts

- Your emotional and/or physical well being
- Your views on the future
- Your time with other children,
- How you use of time
- Your relationship with your husband/wife/partner

5. What support do you get with 'insert name of child'?

Prompts

- What practical support
- What emotional support
- What financial support
- Have you had any other support in the past?
- Is there any support you feel you need but don't/can't get.

6. What do you want healthcare workers to know about the experience of raising a child with cerebral palsy?

- About what it was like when they were diagnosed
- About what it's been like as they've got older
- About day to day life with a child with CP

7. What would you tell other family members who are new to this journey?

Prompts

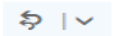
- Why is this important that they know
 - Is there anything you wish you had been told when you had name of child
8. Is there something more you would like to tell me that we've not talked about?

Appendix 7: Email message from Translation Services, Ghana

Emmanuel's document



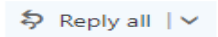
Diver Claire
Fri 7/14/2017, 3:52 AM



Can you send us the translation and of interview 5 if you have done this.
Thank you.
Have a good weekend.
Claire



Asante Emmanuel <ntxea8@exmail.nottingham.ac.uk>
Fri 7/14/2017, 3:35 AM
Lynn Joanne; Diver Claire ↵



Sent Items

Translated transcript of interview 4 verified.

From: Jennifer ama saah Konadu <jamaskay@yahoo.com>
Sent: Friday, July 14, 2017 3:20 AM
To: ntxea8@nottingham.ac.uk
Subject: Emmanuel's document

Dear Emmanuel,
I have had a good time to look through your transcript and translated documents. I am pleased to let you know that the translated English transcript accurately reflects the original transcript. You can go ahead and submit them to your supervisors for their comments. The back translation documents of the English version will be ready by the end of next week.
Best wishes, Jennifer.

BEST REGARDS

Appendix 8: Existing literature on Frank's narrative typologies

AUTHOR	TITLE	COUNTRY	METHODOLOGY	PARTICIPANTS	METHODS	NARRATIVE GENRES CONSTRUCTED	DIFFERENCES IN NARRATIVES
(Bally et al., 2014)	Understanding parental experiences through their narratives of restitution, chaos, and quest: Improving care for families experiencing childhood cancer	Canada	Grounded Theory	12 Mothers 4 Fathers	1. In-depth Interviews 2. Dialogical narrative analysis	Chaos Restitution Quest	Reported that there were no Differences in narratives observed between Mothers and Fathers
(Diver et al., 2013a)	Quest, chaos and restitution: The illness narratives of individuals diagnosed with fibromyalgia syndrome	United Kingdom	Longitudinal Generic Qualitative study	22 Females 1 Male	Semi-structured Interviews Narrative thematic analysis	Quest (active engagement, active disengagement) Chaos Restitution	No reported differences between Male and female Narratives
(Ezzy, 2000)	Illness narratives: time, hope and HIV	Australia	Mixed Methods	Qualitative Sample: 8 women, 38men Quantitative sample: 914	Survey Qualitative Interviews Narrative analysis	Linear Restitution Narrative Linear Chaotic Narratives Polyphonic Narratives	No reported differences between narratives of men and women

(France et al., 2013)	Do men's and women's accounts of surviving a stroke conform to Frank's narrative genres?	United Kingdom	Generic qualitative study	9 Males, 9 Females	Narrative interviews Narrative analysis	Quest(Memoir) Restitution Chaos New proposed genre: Despair	Reported that there were no differences between Men's and Women's narrative
(Nettleton et al., 2004)	Enigmatic illness: narratives of patients who live with medically unexplained symptoms	United Kingdom	Generic qualitative study	5 Men 13 Women	Qualitative interviews Narrative analysis	Chaos only	No reported differences between narratives of men and women
(Pinnock et al., 2011)	Living and dying with severe chronic obstructive pulmonary disease	United Kingdom	longitudinal qualitative study	52 men and women	interviews Thematic narrative analysis	Chaos only	No reported differences
(Reynolds and Vivat, 2006)	Narratives of art-making in chronic fatigue syndrome/myalgic encephalomyelitis: Three case studies	United Kingdom	Case study	3 women	In-depth qualitative interviews Thematic narrative analysis	Quest Only	Not applicable
(Thomas-MacLean, 2004)	Understanding breast cancer stories via Frank's narrative types	Canada	Phenomenological study	12 women	In-depth interviews FGDs Thematic narrative analysis	Restitution Chaos Quest	Not applicable
(Travers and Lawler, 2008)	Self within a climate of contention: Experiences of chronic fatigue syndrome	Australia	Grounded Theory	5 Males 14 Females	Semi-structured interviews Narrative analysis	Restitution (less dominant) Chaos Quest	No reported differences between the narratives of the different heterogeneous groups

(Vroman et al., 2009)	Now let me tell you in my own words: narratives of acute and chronic low back pain	United States of America	Generic qualitative study	143 Adults (Gender number not specified)	Unstructured interviews Thematic content analysis	Chaos only	No reported differences between narratives of participants
(Whitehead, 2006)	Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis	United Kingdom	Hermeneutic phenomenology	17 adults (gender number not specified)	In-depth interviews Narrative thematic analyses	Restitution, chaos and quest	No reported differences between narratives of participants

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