

**PRETERM INFANT CAREGIVERS' PERSPECTIVES ON BASIC INFANT LIFE
SUPPORT TRAINING BEFORE DISCHARGE: A DESCRIPTIVE CASE STUDY AT
A SECONDARY HOSPITAL IN THE WESTERN CAPE, SOUTH AFRICA.**

STUDENT NAME: ANNE BEATRICE AFRICA

Thesis presented in fulfilment of the requirements

For the degree of

Master of Nursing Science

The Department of Nursing and Midwifery

Faculty of Medicine and Health Sciences

Stellenbosch University



Supervisor: Dr Doreen Kainyu Kaura

April 2019

DECLARATION

By submitting this thesis electronically, I Anne Beatrice Africa declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Date: April 2019

Copyright © 2019 Stellenbosch University

All rights reserved

ABSTRACT

Background

Basic infant life support (BILS) includes providing emergency ventilation/breathing and manual cardiac massage/compressions to maintain circulation when a preterm infant has a cardiorespiratory arrest. Preterm infants receive expensive hospitalisation sometimes for two to three months. Smaller preterm infants are discharged in a clinically stable condition. However, these infants still have immature systems which put them at risk of apnoea, infections, and sudden infant death syndrome (SIDS). They are discharged to socioeconomic circumstances that pose risks of inhalation of smoke and unhygienic circumstances, which could result in death within the first week after discharge. Providing preterm infants' parents with BILS knowledge and skills could empower them to save their infants' lives after discharge. International policies, and the Western Cape Department of Health, Kangaroo mother care (KMC) policies are advocating BILS training to preterm infant's parents before discharge. The purpose of this study was to explore the perspectives of preterm infant's caregivers about the pre-discharge BILS skills training at a secondary public hospital in Cape Town Metropole, in Western Cape, South Africa.

Methods

The study was conducted as a qualitative descriptive single case study with two embedded units of analysis. Multimethod data collection included Individual semi-structured in-depth interviews with four parents and four health care professionals and two focus group discussions with midwives. The participants were sampled purposively at a secondary level hospital. The participants in the first unit of analysis were four parents who received the BILS training before discharge. The second unit of analysis included healthcare professionals HCPs who were involved in the BILS training and discharge readiness. Qualitative data analysis was done through coding categorising and theme formation. The principle themes were deduced from the objectives.

Research Findings

Three themes emerged from the first unit of analysis, which included: importance of BILS training, discharge information and development factors identified. Parents reflected on the BILS training they received before discharge and revealed what they learnt about themselves, made them feel empowered, to be able to provide BILS to their preterm infants successfully after discharge. The three themes that emerged from the second embedded unit of analysis included: Rationale for BILS training before discharge and BILS training provided and enhancement factors. The HCPs elaborated on the justification that preterm infants' caregivers need BILS training to be empowered to save their infants' lives after discharge.

Conclusion

The parents of preterm infants' perspectives are that preterm infants are still at risk of life-threatening events which could result in death soon after discharge. The training empowered preterm infant parents. They initially felt anxious, but then felt confident, competent and reassured to provide BILS to their infants successfully after discharge. They felt empowered to enrich family members and communities with BILS information. Barriers and supporting factors were identified from both units of analysis to systematically improve the BILS training programme at the hospital.

Key words

Preterm infants, caregivers, basic infant life support, training, pre-discharge planning

OPSOMMING

Agtergrond

Basiese baba lewensondersteuning sluit in nood toediening van asemhaling, en hart kompressies om sirkulasie te behou, wanneer die vroeggebore baba n kardio-respiratoriese aanval het. Vroeggebore babas ontvang duur hospitalisasie vir omtrent twee tot drie maande. Kleiner vroeggebore babas word ontslaan uit die hospitaal in n kliniese bevredigende stabiele toestand. Nogtans, hierdie babas het nogsteeds onvolgroeide sisteme wat n hoë risiko is vir hierdie babas is en ontbloot hulle om op te hou asemhaal, infeksies te kry en n skielike baba dood sindroom te kry. Hulle word ontslaan na sosioekonomiese toestande wat hoë risiko's van inhalasie van rook, onhigiëniese toestande wat kan lei tot dood binne die eerste week nadat hulle ontslaan is vanaf die hospitaal. Toediening van nood baba lewensondersteuning opleiding van versorgers van vroeg gebore babas kan hulle bemagtig met kennis en vaardighede om hul babas se lewens te red nadat hulle ontslaan was uit die hospitaal. Internasionale beleide en die Wes-Kaapse Departement van Gesondheid se Kangaroo Moeder Sorg beleid beveel aan dat versorgers van vroeggebore babas basiese lewens ondersteuning opleiding kry voordat hul babas ontslaan word uit die hospitaal. Die doel van die studie was om die perspektiewe van die vroeggebore babas se versorgers te eksploreer aangaande die voor ontslag basiese lewens ondersteuning opleiding wat hulle in die sekondêre publieke hospitaal in Kaapstad Metropool, in Wes-Kaap, Suid-Afrika.

Metode

Die studie was uigevoer as 'n kwalitatiewe enkel, beskrywende saak studie met twee ingebedde eenhede van analisering. Veelsydige metodes van data versameling het ingesluit; individuele semi-gestruktureerde indiepte onderhoude met vier versorgers, vier gesondheidsprofessionele versorgers en twee fokus groep besprekings/onderhoude. Die monster van deelnemers was doelbewus gekies by die sekondêre vlak hospitaal. Die deelnemers in die eerste eenheid van analisering was vier versorgers wat basiese baba lewens ondersteuning opleiding ontvang het voordat hulle babas ontslaan was uit die hospitaal. Die tweede eenheid van analisering was

gesondheidsorg professionele versorgers wat betrokke was in die basiese lewens ondersteuning opleiding en ontslaan gereedheid van die ouers. Data analisering was gedoen deur kodering, kategorisering en tema vorming. Die hoof temas was afgelei van die doelwitte.

Resultate/Navorsing Bevindinge

Drie temas het na vore gekom wat insluit; die belangrikheid van basiese baba lewens ondersteuning opleiding, ontslag informasie en ontwikkeling faktore was geïdentifiseer. Ouers het gereflekteer op die basiese baba lewens ondersteuning opleiding wat hulle ontvang het voordat hulle ontslaan was van die hospitaal. Hulle het geleer omtrent hulleself; hulle het emotioneel bemagtig gevoel en hulle het basiese baba lewens ondersteuning suksesvol toegedien nadat hulle babas ontslaan was uit die hospitaal. Verder, drie temas het na vore gekom onder ingebedde eenheid van analisering twee het ingesluit; basiese baba lewens ondersteuning opleiding voor ontslag, basiese baba lewens ondersteuning toegedien en verbetering faktore. Die gesondheidsorg professionele versorgers het uitgebrei op die regverdiging dat vroeg gebore babas se ouers basiese baba lewens ondersteuning opleiding benodig om hulle babas se lewens te red nadat hulle babas ontslaan was vanaf die hospitaal.

Slotsom

Ouers van vroeggebore babas se perspektiewe is dat vroeg gebore babas nogsteeds 'n hoë risiko van lewens bedreigende gebeurtenisse is wat kan opeindig in dood binnekort na ontslag vanaf die hospitaal. Hulle het aanvanklik anstig gevoel, maar het selfvertroue gewen, bevoeg en gerusgestel gevoel om baba lewensondersteuning suksesvol toe te dien na ontslag vanaf die hospitaal. Hulle is bemagtig om familie lede en gemeenskappe te bemagtig met basiese baba lewensondersteuning informasie. Hindernisse en ondersteuning faktore was geïdentifiseer vanaf albei eenhede van analisering om die basiese baba ondersteuning opleiding program sistematies te verbeter.

Sleutelwoorde

vroeggebore babas, versorgers, basiese baba lewensondersteuning opleiding, voor-ontslag beplanning

ACKNOWLEDGEMENTS

I would like to express my sincere thanks to:

To our Almighty God and Heavenly Father who created me and has given me all my abilities, through Jesus Christ who strengthens me.

To my Study Supervisor, Dr Doreen Kainyu Kaura, for your selfless patience, excellent guidance and academic support.

To the Western Cape Department of Health and the senior management of Mowbray Maternity Hospital, thank you for granting me the opportunity to conduct my research at the hospital.

To the medical fraternity, nurse managers, my colleagues in the education department and all the participants, without you I would not have been able to conduct the research. I am absolutely blessed to be part of such a dynamic team.

To Mrs Karin Moore, my manager, thank you for being such a caring and dynamic leader who understands the importance of ongoing professional development of your team.

I dedicate this thesis to:

My daughter Kelci Africa, my family and friends for your ongoing love and support.

TABLE OF CONTENTS

Declarationi

Abstract ii

Opsomming..... iv

List of tables..... xi

Abbreviations..... xii

1.1.	Introduction.....	1
1.2.	Significance of the problem.....	1
1.3.	Rationale	1
1.4.	Problem statement.....	2
1.5.	Research question.....	3
1.6.	Research aim	4
1.7.	Research objectives	4
1.8.	Research methodology.....	4
1.9.	Research Design	4
1.9.1.	Study setting.....	5
1.9.2.	Population and sample	6
1.9.3.	Data collection tool	6
1.9.4.	Pilot interview.....	6
1.9.5.	Trustworthiness	7
1.9.6.	Data collection	7
1.9.7.	Data analysis	8
1.9.8.	Ethical considerations	8
1.10.	Chapter summary	8
2.1.	Introduction.....	9
2.2.	Electing and reviewing the literature	9
2.3.	Risk factors for preterm infants	10
2.4.	Basic infant life support skills training	12
2.5.	Caregivers of the preterm infants.....	14
2.5.1.	Caregivers/parents and guardians of preterm infants.....	14
2.5.2.	Caregivers – health care professionals -Midwives	15
2.5.3.	Care givers- Healthcare professionals'-Doctors	17
2.5	basic infant life support guidelines	18
2.5.4.	American Heart Association (AHA) BILS 2010 guidelines.....	18
2.5.5.	Resuscitation council (UK) guidelines 2015 - pediatric basic infant life support. 19	

2.5.6.	Helping babies breathe (HBB)	20
2.5.7.	Western Cape Department of Health 2030 Healthcare goals	21
2.6.	Conclusion	21
3.1.	Introduction	23
3.2.	Research approach	23
3.3.	Study setting	24
3.4.	Research design	27
3.5.	Population and sampling	30
3.5.1.	<i>Inclusion criteria</i>	30
3.5.2.	<i>Exclusion criteria</i>	31
3.6.	Data collection process	31
3.6.1.	<i>Approval obtained</i>	31
3.6.2.	<i>Recruitment</i>	31
3.6.3.	<i>Data collection tool- interview guide</i>	33
3.6.4.	<i>Pilot interviews</i>	34
3.7.	Data collection methods	36
3.7.1.	Individual interviews	37
3.7.2.	Focus groups	39
3.7.2.1.	Focus group one	40
3.7.2.2.	Focus group two	41
3.7.2.3.	Field notes	41
3.8.	Data analysis	42
3.8.1.	<i>Interpreting the case</i>	42
3.8.2.	<i>Organizing and preparation of the data</i>	42
3.8.3.	<i>Transcription of interviews</i>	42
3.8.4.	<i>Immersion with the data</i>	43
3.8.5.	<i>Coding interview transcripts</i>	43
3.8.6.	<i>Content analysis</i>	44
3.8.6.1.	<i>Logical grouping of codes into categories</i>	44
3.8.6.2.	<i>Theorising the case study</i>	44
3.8.6.3.	<i>Reduction of volumes of data</i>	44
3.9.	Trustworthiness	45
3.9.1.	Credibility	46
3.9.2.	Confirmability	46
3.9.3.	Dependability	47
3.9.4.	Transferability	47
3.10.	Ethical considerations	48

3.10.1. Permission from internal review boards	48
3.10.2. Consent and Autonomy	48
3.10.3. Beneficence.....	49
3.10.4. Justice	49
3.10.5. Confidentiality and privacy	50
3.10.6. Social value	50
3.10.7. Collaborative Partnership.....	50
3.10.8. Scientific Validity.....	51
3.11. Summary.....	51
3.12. Conclusion.....	52
3.13. Operational definitions	52
4.1. Introduction.....	54
4.2. Demographic data	54
4.3. Embedded Unit of Analysis One: parents of preterm infants	57
4.3.1. <i>Theme one: Basic infant life support training</i>	59
4.3.1.1. <i>Subtheme: Feeling empowered</i>	59
4.3.1.2. <i>Subtheme: Empowering others</i>	61
4.3.2. Theme two: discharge information	62
4.3.2.1. <i>Subtheme: ongoing education</i>	62
4.3.2.2. <i>Subtheme: sharing information</i>	63
4.3.3. Theme three: supporting factors	63
4.3.3.1. <i>Subtheme: educational Levels</i>	63
4.3.3.2. <i>Subtheme: language barriers</i>	64
4.3.3.3. <i>Subtheme: Visualization of demonstrations</i>	65
4.3.3.4. <i>Subtheme: information overload</i>	65
4.4. Embedded unit of analysis two: Perspectives of HCPs on the BILS training	66
4.4.1. Theme one: Motivation for BILS training before discharge	68
4.4.1.1. <i>Subtheme: empowering of preterm infant parents</i>	68
4.4.1.2. <i>Subtheme: Preterm infants risk factors of preterm infants after discharge</i>	69
4.4.2. Theme two: Providing BILS training	71
4.4.2.1. <i>Subtheme: Perspectives on providing BILS training</i>	71
4.4.2.2. <i>Subtheme: identifying danger signs</i>	75
4.4.2.3. <i>Subtheme: Empowering of parents</i>	76
4.4.2.4. <i>Subtheme: Effectiveness of BILS training</i>	77
4.4.2.5. <i>Subtheme: challenges providing BILS training</i>	80
4.4.3. Theme Three: supporting the BILS training programme.....	83
4.4.3.1. <i>Subtheme: developing a BILS training video</i>	84

4.4.3.2. Subtheme: keep BILS training basic	85
4.4.3.3. Subtheme: developing individual plans	86
4.4.3.4. Subtheme: implementing BILS Support groups on social media	86
4.4.3.5. Subtheme: Implementing of BILS training to all birthing institutions	87
4.4.3.6. Subtheme: Monitoring of BILS training.....	88
4.5. Summary	90
4.6. Conclusion.....	91
5.1. Introduction.....	92
5.2. Discussion	92
5.3. Perspectives of parents of preterm infants.....	93
5.4. Healthcare Professionals' Perspectives	95
5.4.1. Barriers and Supporting factors	97
5.5. Limitations of the study	101
5.6. Conclusions	102
5.7. Recommendations.....	102
5.7.1. Perspectives of parents who received the BILS training.....	103
5.7.2. Insights from Healthcare professionals	103
5.8. Barriers and supporting factors identified.....	104
5.9. Dissemination of research findings	105
5.10. Future research	106
6. REFERENCES	
7. APPENDICES	
Appendix 1: Ethical approval from Stellenbosch University.....	111
Appendix 2: Permission obtained from institutions / Department of Health.....	112
Appendix 3: Parents Of Preterm Infants Who Received The BILS Skills Training Before Discharge Consent: English	115
Appendix 4: Doctors' Consent: English.....	118
Appendix 5: Midwives' Consent: English	122
Appendix 6: Interview Guide Parents.....	125
Appendix 7: Interview Guide Midwives focus group	126
Appendix 8: Confidentiality agreement with data transcriber (if applicable) / permission for use of an instrument.....	128
Appendix 9: Extract of transcribed focus group discussion: midwives 2	129
Appendix 10: Declarations by Language and Technical Editors	131

List of tables

Table 1.1: Leading causes of infants' deaths under one year (Reid et al., 2016:361)	1
---	---

LIST OF FIGURES

Figure 1: Metro West District Health Services (Moore, 2018)	26
Figure 2; Types of case study design (Yin, 2014)	29
Figure 3: Three Principle Themes on the phenomenon	90

ABBREVIATIONS

AAP	American Academy of Paediatrics
BILS	Basic infant life support
HCPs	Health care professionals
SIDS	Sudden infant deaths syndrome
SIV	Self-instruction video
KMC	Kangaroo Mother Care
MMH	Mowbray Maternity Hospital
NNUs	Neonatal Units
SDGs	Sustainable Development Goals
WCDOH	Western Cape Department of Health
WHO	World Health Organization

1. CHAPTER ONE

FOUNDATION OF THE STUDY

1.1. Introduction

Preterm infants who need specialised healthcare in neonatal units are often at an increased risk of having cardiorespiratory arrests after discharge (Brannon, White, Kilcrease, Richard, Spillers & Phelps, and 2009:133). Furthermore, Jefferies (2014:32) asserts that very low preterm infants are still at risk of having apnoea spells up to 44 weeks' gestation after discharge. There is a need to provide the parents with knowledge and skills necessary to initiate Basic infant life support (BILS) when needed while they are with the infants at home.

BILS in this study is defined as providing emergency ventilation/breathing and manual cardiac massage to maintain circulation when a preterm infant has a cardiorespiratory arrest (McFerrin, 2008:50). According to Jefferies (2014:32), preterm infants are babies born before 37 weeks' gestation. These babies do not usually have fully developed organs such as the lungs and heart. They are vulnerable to cardiorespiratory distress and may require resuscitation often.

This study was conducted in an urban level two setting, at a public secondary hospital in Cape Town, Western Cape, South Africa. The hospital admits preterm infants and discharges them when stable, to parents who have received BILs training as discharge support.

A synopsis of the reviewed literature will be discussed below. The rationale, significance of the problem, problem statement, research objectives, ethical considerations and research design are also discussed below. The purpose of this study was to describe the perspectives of caregivers of preterm infants regarding the BILS skills training programme.

1.2. Significance of the problem

In September 2015, the United Nations General Assembly accepted the 17 Sustainable Development Goals (SDGs) and 169 targets. SDG three (3) aims to eliminate avoidable deaths of preterm infants and children under five years and to decrease the neonatal mortality rate to 12 per 1000 live births (WHO, 2017). There is

a need to identify the causes of these deaths and develop innovative ways to address the sustainability of these goals.

Smaller preterm infants who are medically stable are discharged home to prevent them being exposed to nosocomial infections and resistant pathogens in hospital (Jefferies, 2014:32). As a preventive precaution there is a need to ensure that the parents feel confident with skills to help the neonates' breath when they are discharged home. Discharge refers to when there is no longer a need for an infant to be hospitalised, or to receive health care in a facility, once their treatment has been completed (McQuoid-Mason & Dada, 2011:99). However, after discharge there is a need for infant monitoring and surveillance to ensure support post discharge and prevent morbidity and further complications.

Many preterm infants with immature immune systems are discharged to low socioeconomic circumstances where they are at risk to be exposed to pathogens such as respiratory syncytial virus (RSV) and streptococcus pneumonia (Premji, Young, Rogers & Reilly, 2012:57). It is therefore important to ensure that the parents of these infants are equipped with knowledge to identify danger signs and respond accordingly when they are with the neonates at home.

Reid, Hendricks, Groenewald and Bradshaw, (2016: 359) argue that accurate infant mortality data are key to plan health interventions to reduce infant deaths. Yet, Reid et al. (2016:364) also highlight that despite many routine data systems such as: the child healthcare identification programme (CHIPP) and perinatal problem identification programme (PIP), South Africa's (SA) child & infant mortality data are incomplete. Gaps have been identified; therefore, further research is required to assess why children are dying out of hospital from curable conditions. Empowering women with BILS skills before their infants' discharge was seen as one of the ways to prevent death from curable conditions through early identification and treatment (Reid et al., 2016:364).

According to Metro West geographical service area Western Cape, South Africa, in 2011, data was released on the under-fives' mortality which determined the causes of death as shown in table 1.1 (Reid et al., 2016:359). The following table reveals the leading causes of infants' deaths.

Table 1.1: Leading causes of infants' deaths under one year (Reid et al., 2016:361)

Out of hospital new-born deaths 0-28days		Out of hospital Infant deaths >28days–1 year	
Pneumonia	24 (34.8%)	Pneumonia	120 (53.8%)
Ill-defined	14 (20.3%)	Gastroenteritis	41 (18.4%)
Prematurity	5 (7.2%)	Other natural causes	10 (4.5%)
Sudden infant death	3 (4.3%)	Other injuries	6 (2.7%)

According to Reid et al. (2016:362), the high statistics of out-of-hospital infant deaths are alarming. Providing education such as BILS skills, will ensure that parents are well prepared before the preterm infant is discharged home and may enhance their problem-solving skills as well as emotionally prepare them to care for their infants after discharge (Bracht, O'Leary, Lee, & O'Brien, 2013:115).

In conclusion, there is a need for BILS training for parents of preterm infants in order to enable them to support their infants in case of emergencies, while identifying the danger signs which will require the mother to seek help.

1.3. Rationale

The rationale for this study was twofold: the researcher who worked in the neonatal intensive care unit, high care unit and kangaroo mother care ward at a public secondary hospital, found that preterm infants were reported dead soon after discharge.

Secondly, during clinical practice the researcher witnessed a need for resuscitation training on two different occasions when two mothers, who had been discharged, came back into the neonatal unit with their preterm infants who had stopped breathing at home. On assessment, both infants were dead on arrival. Further, a senior neonatologist noticed an increase in sudden infant deaths in a kangaroo mother care ward at the secondary hospital and recommended that the BILS training for caregivers of preterm infants and high-risk infants be implemented.

Further, according to Brannon et al. (2009:33), many hospitals internationally have policies that parents and carers should be equipped with BILS skills before discharge to enable them to confidently assist the infant when the need arises.

It is also part of the Western Cape Department of Health (WCDOH) Kangaroo Mother Care policy that parents receive BILS skills training before discharge, in order for them to be equipped to save their infant's life when the need arises (WCDOH, 2011:48). However, BILS skills training is not being provided to parents of preterm infants before discharge at all institutions in the Western Cape, Cape Town, South Africa.

The researcher identified a need to explore and investigate the perspectives of caregivers such as parents, doctors and midwives about the BILS skills training programme before discharge. The BILS skills training programme is part of the discharge plan for preterm infants at Mowbray Maternity Hospital, a public secondary level hospital in Cape Town, South Africa.

1.4. Problem statement

The purpose of the Western Cape Department of Health's (WCDOH) transformation strategy is to improve the health of the people that it serves. The improvement must reflect from quantitative (measurable) to qualitative reduction of the infant mortality rate (WCDOH, 2017:1-2).

According to Brannon et al. (2009:137), sudden infant deaths (SIDS) happen within the first few months after discharge, therefore effective BILS skills training to parents of preterm infants is vital before discharge home, to ensure that caregivers can provide BILS when preterm infants stop breathing at home.

The World Health Organisation (WHO) asserts that an estimated 270,000 preterm infants die globally within the first month of life due to them being discharged to low socioeconomic circumstances which pose risk factors for preterm infants to contract infections (WHO, 2017:1).

The World Health Organisation also asserts that preterm infants are at risk of infections such as pneumonia and gastroenteritis due to exposure to low socioeconomic circumstances, environmental hazards such as air pollution caused by smoke, unhygienic circumstances and poor sanitation (WHO, 2017:1). It is therefore important to ensure that the parents are aware of the dangers to their infants and equipped to ensure that they are ready to handle any emergencies.

Prolonged hospitalisation results in parents of preterm infants experiencing anxiety, which they could be ill prepared for, and which could result in vulnerable infants being at risk of neglect as many infants are discharged to low socioeconomic circumstances (Jefferies, 2014:31).

Providing education such as BILS skills will ensure that caregivers/parents are well prepared before the preterm infant is discharged home and may enhance their problem-solving skills as well as decrease their anxiety levels to prepare them to care for their infants after discharge (Bracht et al., 2013:115; Jefferies, 2014:31). Yet, BILS skills training is not rendered to parents of preterm infants before discharge at all institutions in Western Cape, South Africa.

The BILS skills training programme for parents of preterm infants was implemented in 2005, initially only for high risk infants but became part of the discharge plan in 2009 for all preterm infants and high-risk infants at the only public maternity secondary hospital in the Metro West geographical area.

Anecdotal reports received from a medical officer, neonatologists and patients, indicated that the BILS skills training programme at the Secondary Level hospital is effective. However, no formal studies have been done on the BILS skills training to preterm infant caregivers at this Secondary Public Hospital in the Cape Town Metropole in the Western Cape (WC), South Africa. In addition, the researcher did not find literature on the perspectives of caregivers regarding the BILS skills training before discharge.

Therefore, this research explores the perspectives of parents and HCPs about the BILS training the parents of preterm infants before discharge. The lack of evidence on perspectives of caregivers who have undergone such training leads to lack of understanding of the effectiveness of this training being offered in the WC province.

1.5. Research question

What are the perspectives of caregivers of preterm infants about the BILS Skills training programme before discharge at a secondary public hospital in the Cape Town Metropole in the Western Cape, South Africa?

1.6. Research aim

The aim of the study was to explore the perspectives of the caregivers about the pre-discharge BILS skills training for parents of preterm infants at a public hospital in the Cape Town Metropole, in the Western Cape, South Africa.

1.7. Research objectives

The research objectives for this study are:

- RO 1** To describe the perspectives of parents of preterm infants who received the BILS skills training before discharge in a public hospital in the Cape Town Metropole in the Western Cape, South Africa.
- RO 2** To explore the perspectives of healthcare professionals, who are involved with discharge readiness of preterm infants in a public hospital in the Cape Town Metropole, on the BILS skills training.
- RO 3** To describe barriers and supporting factors about the BILS skills training programme for the caregivers of preterm infants before discharge in a public hospital in the Cape Town Metropole.

1.8. Research methodology

A qualitative study was chosen, as the constructivist perspectives described the phenomenon best. Grove, Gray & Burns (2015:68) recommend that the qualitative researcher describes the perspectives of the phenomena. In this study the researcher discovered the perspectives of the caregivers about the BILS skills training in-depth, as the participants have their own distinct or exclusive perspectives in view of time and context to provide a holistic picture.

1.9. Research Design

Yin (2014, 51) states that different case studies such as an intrinsic case study, instrumental case study and collective case study exist. The intrinsic case study is used to study a unique phenomenon therefore, the researcher must be able to define the uniqueness of the phenomenon and justify what distinguishes it from the others.

According to Rule & John (2011:8), the focal point of an intrinsic case study is on the case due to it being intriguing. In contrast, an instrumental case study is investigating

the case for a general wider issue. Dissimilarity between other case studies such as the exploratory, explanatory and descriptive exist (Rule & John, 2011:8).

A descriptive case study provides a comprehensive, in-depth description within its setting. Whereas, an exploratory case study investigates a phenomenon that has not been researched before and provides a foundation for further studies (Rule & John, 2011:8). Contrary, an explanatory case study aims to describe the events in a case study, or the reasoning for its occurrence (Rule & John, 2011:8).

The single case study was chosen for this study as it described the phenomenon in-depth and currently this is the only context within which the perspectives of the caregivers of preterm infants about the BILS training was explored (Yin, 2014: 51).

This descriptive single case study approach best described the perspectives of caregivers of preterm infants about the BILS Skills training before discharge at the secondary hospital, in their normal setting (Rule & John, 2011:60). The purpose of the study was to explore the perspectives of the caregivers about the pre-discharge BILS skills training for caregivers of preterm infants at a secondary public hospital in the Cape Town Metropole, in the Western Cape, South Africa.

The descriptive single case study consisted of two units of analysis (Yin, 2014: 50). According to Yin (2014:50), the unit of analysis is the source of information such as the different caregivers, which are the parents, or guardians of the preterm infants, and health care professionals (HSPs) such as doctors and midwives. The single case study with two embedded units of analysis, was used with multiple methods to explore the perspectives of caregivers of preterm infants, on BILS training.

1.9.1. Study setting

The study was done at Mowbray Maternity Hospital, a Secondary Public Hospital in Cape Town, Western Cape, South Africa. In South Africa, healthcare is governed at National, Provincial and District or Regional level. Western Cape Province is one of nine Provinces. Western Cape Health Care comprises six (6) districts, which have primary care facilities such as clinics, community health care centres and Midwife Obstetric Units (MOUs) (Republic of South Africa, 2015).

Secondary level care services are provided by thirty-two district hospitals and six (6) regional hospitals in the Western Cape. Mowbray Maternity Hospital, the Secondary Hospital where the study was conducted is a regional hospital within the Metro West District Health Services with many referrals from five (5) busy Midwife Obstetric Units (MOUs) and low risk patients living within the catchment area of the hospital (Republic of South Africa, 2015).

1.9.2. Population and sample

A population is defined as the entire group of individuals such as the caregivers at an institution, the secondary hospital, who were involved in an event with mutual defining characteristics such as the BILS training programme (Polit & Beck, 2014:51; Grove et al., 2015:509).

A purposive sample consisted of caregivers such as parents of preterm infants who received the BILS training, and health care professionals such as doctors and midwives who were involved in the discharge planning or training of the preterm infants' caregivers, before discharge.

1.9.3. Data collection tool

Semi-structured interview guides were utilised to ensure that the researcher posed a fixed set of conversational questions to the participant allowing no fixed answers (Grove et al., 2015:512). Simplified semi-structured questions were compiled for the individual parents of preterm or low birth weight infants who had BILS Skills training, and the HSPs who were involved in the BILS training to accommodate all educational levels.

The researcher commenced the first introductory question with “tell me more about yourself” to build a rapport with the participants and to get demographic information from the clients. Semi-structured data collection interview guides were used for both in-depth interviews and focus groups.

1.9.4. Pilot interview

Two pilot interviews were conducted. According to Yin (2014:240), the value of the pilot interview was to develop, test and refine the planned research questions and procedures that were used in the official case study. Two pilot interviews were

conducted with one parent who received the BILS training, and one midwife who provided the BILS training to caregivers before discharge. The data collated during the pilot interviews were included in the study.

1.9.5. Trustworthiness

The researcher observed the principles such as scholarly rigour, transparency and professional ethics during qualitative research, to achieve confidence and trustworthiness within the research community (Rule & John, 2011:107). Rule and John, (2011:107) cited Guba (1981) who refers to trustworthiness being accomplished when credibility, confirmability, dependability and transferability are noted.

1.9.6. Data collection

Once ethical approval was obtained from the Health Research Ethics Committee of Stellenbosch University, approval was also obtained from the Western Cape Department of Health to conduct the study at the secondary hospital. Furthermore, institutional permission was obtained. Data collection was done during the months from July 2018 to September 2018 at the Secondary Public Hospital in Cape Town, Western Cape, South Africa.

The researcher applied triangulation and utilised three data collection sources, in the case study (Rule & John, 2011:63; Grove et al., 2015:513). Multiple sources of information such as individual interviews and focus group discussions, were used for a wide gathering of information needed and provided an in-depth picture (Yin, 2014:119).

According to Yin (2014: 118-119), a single source of evidence, such as only individual in-depth interviews with parents who received the BILS training, was not suggested for case studies as it poses concerns of quality of the study. Therefore, multiple sources, such as in-depth individual interviews with four parents and four doctors, were used. Furthermore, two in-depth focus group discussions with four midwives per group about the pre-discharge BILS skills training sessions to parents of preterm infants were done to ensure overall quality of the study (Yin, 2014:119; Burns & Grove, 2011:513).

1.9.7. Data analysis

Burns & Grove (2011:93) contend that qualitative data analysis occurs simultaneously with data collection. The researcher understood during data analysis that it is a creative and intellectual process where she needed to work with the data from data collection, to find patterns of meaning (Rule & John, 2011:75).

The researcher applied the following steps, interpreting the case, organizing and preparation of the data, transcription of interviews, immersion with the data, coding interview transcripts, content analysis, logical grouping of codes into categories, theorising the case study and reduction of volumes of data during data analysis.

1.9.8. Ethical considerations

The ethical considerations such as, right to self-determination, right to confidentiality and anonymity and right to protection from discomfort and harm were observed during the descriptive case study. The researcher ensured that all advantages and disadvantages were explained to all participants when informed written consent was obtained. All participants were informed that they would be participating voluntarily in the case study and that they could withdraw from the study at any time without any consequences. No personal information about participants were disclosed and their privacy was protected.

1.10. Chapter summary

This chapter discussed the foundation of the study synoptically. The introduction, significance of the problem, rationale, problem statement, research question, aim, research objectives, research methodology, research design and ethical considerations were briefly discussed. In chapter two the literature review pertaining to the study will be discussed.

2. CHAPTER TWO

LITERATURE REVIEW

2.1. Introduction

The literature review was commenced to appraise the current knowledge regarding the perspectives of caregivers on the BILS skills training of preterm infants' parents before discharge, and to synthesise what is known and unknown about the topic (Grove, Gray & Burns 2015:163).

According to Grove, Gray & Burns (2015:22), a systematic review is a method used to scrutinise research reports in a constructive and comprehensive manner to identify, obtain, and critically appraise good quality research to ensure that the best evidence practice is applied. Grove, et al. (2015:287) refer to reliability as observing the consistency of the measurement method to ensure good quality evidence. The process observed systematic reviews, appraising the quality and reliability of evidence.

As mentioned in the rationale for this study, the researcher could not find literature related to the perspectives of preterm infants' caregivers on the basic life support training before discharge. However, the literature review continued until after the results of the study were available, to prevent prejudice in the study (Grove et al., 2015:164).

Furthermore, the international and national BILS guidelines were reviewed to justify why the Resuscitation Council (UK) Paediatric basic infant life support Guideline (2015) was used for the BILS skills training programme, before discharge, to parents of preterm infants at a Secondary Public Hospital in Cape Town, South Africa.

2.2. Electing and reviewing the literature

A scope of literature was done from databases which included EBSCO databases, Econlit, with the links CINAHL, Google scholar, ERIC, academic search, health source nursing/academic edition, and PubMed among others. Search terms such as parents or caregivers, basic life support, cardiopulmonary resuscitation, training, preterm infants, pre-discharge planning and infant mortality.

The supporting literature reviewed was on pre-discharge planning, preterm infants, the caregivers such as parents, doctors and midwives to determine what is known and to identify gaps about all the caregivers involved in BILS skills training before discharge of preterm infants. In addition, the international, national and provincial infant mortality rates were reviewed to determine the need for the BILS skills training for caregivers of preterm infants.

Only literature regarding BILS skills training and supporting literature within the last ten years was selected to be used for this study. Mostly older quantitative studies were found to assess the preterm infants' parents' BILS skills and knowledge of BILS skills training that they received before discharge. No studies on perspectives of preterm infants' caregivers were found; however, supporting literature such as the infant mortality rate, and supporting literature about pre-discharge plans were selected.

These were searched for relevant literature. Hard copies of International and National guidelines, articles and journals were included. Primary and secondary literature was included. Many articles were found on the electronic databases but were excluded due to being older than 10 years. Reference lists of articles were perused, and relevant articles were identified from reference lists.

2.3. Risk factors for preterm infants

Jefferies, (2014:34) emphasises the importance that parents of preterm infants be taught BILS skills before discharge to resuscitate their infants after discharge when they stop breathing.

In the past, preterm infants were discharged at a weight of 2000 grams (AAP, 2008:3). However, today randomised controlled trials have shown that preterm infants could be discharged earlier without adverse health effects (AAP, 2008:3). This requires intensive BILS training of the parents before discharge in order to prepare them for any eventualities. According to AAP, (2008:7) intensive training starts at admission of the infant to the NNU. Parents are involved in the care of their infants and BILS training to parents is often repeated due to the preterm infant's length of stay in hospital.

Further, Jefferies, (2014:32) and AAP (2008:3) contend that discharge readiness is recognised when the preterm infant can maintain his/her body temperature, be able to

feed well, and is able to gain weight steadily, controls breathing and has respiratory stability and parents are involved and trained to care for the infant after discharge.

Premji, Young, Rogers & Reilly (2012:61) report that apnoea deaths of preterm infants after discharge were isolated events and the causes could not be identified. However, due to the immaturity of the autonomic brain stem, this can result in sudden infant deaths of preterm infants. The AAP (2008:3) agrees that the respiratory immaturity of preterm infants could be up to 44 weeks gestational age. Preterm infants born at a much earlier gestation often take longer to meet their physiological competencies compared to term infants. Preterm infants will then require more attention compared to term infants post discharge (AAP, 2008:3).

Even though preterm infants are discharged in a satisfactory condition, late preterm infants are three times at greater risk of infection after discharge, due to their immature systems compared to term infants. Late preterm infants are at risk of apnoea due to immature respiratory reflexes, immature coordination of sucking, swallowing and breathing reflexes (Premji et al., 2012:61-63).

An estimated 15 million preterm infants are born per year, of which one million die due to prematurity. Approximately, 270 000 infants and preterm infants die within the first month of life due to respiratory infections caused by smoke inhalation, diarrhoea, caused by lack of access to clean water, sanitation and poor hygienic circumstances (WHO, 2017:1).

Doherty, Kroon, Rhoda & Sanders, (2016:672), reveal that HIV/AIDS is no longer the leading cause of the high 'under-five' mortality rate in South Africa due to the highly effective antiretroviral therapy. The Prevention of Mother to Child Transmission Programme (PMTCT) resulted in the decrease of the mother-to-child-transmission rate (at 4-8 weeks of infant age) to around 2.6% (Doherty et al., 2016:672). The leading causes now are gastroenteritis (15%) and pneumonia (13%). A retrospective study carried out in 2011 amongst the under-fives in the Metro West geographical area revealed that 384 (55%) infants died after discharge home (Reid, et al., 2016: 359). For infants under 1year in age, the deaths caused by pneumonia out of hospital were 144 (49%) (Reid et al., 2016: 359).

Sudden unexplained infant death (SUID) is defined as deaths occurring during sleep that happen unexpectedly and are unpredicted and cannot be clarified after cases have been inspected. Sudden Infant Deaths SIDS are described as deaths occurring unexpectedly during sleep (AAP, 2011:1030). Therefore, Dowling, Barsman, Damato and Czeck (2015:209 - 211) and Judith, Gooding, Cooper, Blaine, Frank, Howse & Berns (2011:1) state that caregivers should be informed about SIDS and be educated about safe sleeping practices such as: supine positioning of preterm infants who are in a stable condition, during sleep from 32 weeks' gestation.

The infant mortality rate is three times higher in preterm *infants* compared to term infants when positioned supine, but it is seven times higher if placed on the stomach (Dowling et al., 2015:209-210). In 2011 the AAP expanded the recommendations to prevent SIDS, to position infants on their backs (supine positioning) during sleep on a firm surface; advocate breastfeeding; rooming-in but no co-bedding; immunise against preventable childhood diseases as scheduled; prevent passive smoking; alcohol and the use of illicit drugs (AAP, 2011:1030).

The information on preterm infant mortality, causes of morbidity and mortality require preparedness for parents of preterm infants after discharge in order to prevent illness and be prepared in case of cardiopulmonary distress or arrest.

2.4. Basic infant life support skills training

Jefferies (2014:31) recommends that a well-planned pre-discharge plan is to include parents in the caring for the infant while he/she is still hospitalised to ensure smooth transition to home and safe, effective care after discharge

According to Grove et al. (2015:241), a randomised control trial (RCT) is recognised as the best research design, to test the effectiveness of treatment or an intervention to reduce potential bias. Participants are randomly assigned to the treatment/intervention and a control group created, to decrease the risk of bias (Grove et al., 2015:241). A randomised control trial was carried out at the Baylor University Medical Center at Dallas in 2009, where all parents of preterm infants received basic infant BILS skills training before discharge. The two control groups included parents who watched a BILS skills training video within 48 hours before instructor-led training,

and the parents who did not watch a video but only had instructor-led training (Brannon et al., 2009:133).

The parents in this study completed a checklist test within seven days after they had the BILS training and before their infants were discharged (Brannon et al., 2009:133). The skills that were evaluated included: assessment, ventilation and chest compressions were rated as good, fair or fail. To pass, these parents had to be rated good or fair in all skills (Brannon et al., 2009:133).

The study revealed that all 10 participants, who watched the video prior to instructor led training, performed well. Approximately, nine out of 13 in the control group passed the training. Furthermore, 80% of the video participants were rated good in all sections, compared to the control group where only 7% were evaluated good in all sections. The study shows a limitation of the study design was that it “simply compared more training” with “less training,” indicating the need to explore other variables such as effectiveness of the training (Brannon et al., 2009:133).

Another study, an observational survey-based study, was performed in a quaternary academic paediatric hospital from June 2008 – December 2009. The study method was a telephonic survey, which was conducted at 1, 3 and 6 months to assess the retention of BILS skills, knowledge and comfort levels of the BILS skills of parents of preterm infants. Furthermore, Knight, Wintch, Nichols, Arnolde & Schroeder (2013:9) also investigated if the parents shared the BILS skills training video kit with their family members, which could facilitate information sharing with the community (Knight, Winch, Nichols, Arnold & Schroeder, 2013:10)

Equally important, 82% of participants watched the video at least once after discharge, and 79% of participants shared the kit with at least two other family members or friends (Knight et al., 2013:9). A total of 72 or 74 (97%) of the participants who were surveyed were either “satisfied” or “very satisfied” with the programme (Knight et al., 2013:9).

Knight et. al. (2013:9) also argue that availing the “CPR Anytime Kit™ to parents/families of high-risk preterm infants before discharge, ensures sustained levels of BILS knowledge and confidence in the skills. Knight et al. (2013:9) also contend that training barriers pose risks of inconsistency and the effectiveness of BILS skills training before discharge is short term. However, the American Heart Association

(AHA), “CPR Anytime Kit™” is a self-instruction video kit that provides the parents with information to identify that the preterm infant is unresponsive and provides step by step BILS skills successfully (Knight et al., 2013:9). In addition, a mannikin is also available in the kit for parents to practice the BILS skills (Knight et al., 2013:9).

2.5. Caregivers of the preterm infants

Caregivers in this study, include the caregivers/parents or guardians of preterm infants who received the BILS skills training before discharge. Other caregivers are the health professionals, such as doctors and midwives who were involved in BILS skills training to caregivers/parents and or guardians taking care of the preterm infant during the transition period before discharge and after discharge during the follow up period (Jamieson & Lake, 2013:7).

2.5.1. Caregivers/parents and guardians of preterm infants

Person or family-centred care is advocated in neonatal units (NNU's) by involving and educating parents to find their own strengths, to confidently take care of their infants after discharge (Bracht et al., 2013:115).

According to Brannon et al., (2009:138) BILS skills are psychomotor skills, therefore caregivers need to practice more on mannequins to ensure that they are competent to provide BILS skills to preterm infants after discharge. The participants in the study conducted by Brannon found sealing the mouth and nose of the mannequin to give ventilation/breathing, challenging (Brannon et al., 2009:138).

In addition, Brannon et al. (2009:138) state that many participants did not give effective chest compressions due to fear of causing injury to the infant. The authors (2009:138) also state that the use of a video to demonstrate BILS skills could accommodate all parents with different reading and language barriers, to ensure more effective learning. However, Brannon et al. (2009:133) reason that parents of preterm infants who receive a pre-discharge education about aspects such as BILS, administration of medication, and education on other topics, could become overwhelmed with an overload of information which could result in less effective learning.

Brannon et al. (2009:133) further state that the utilisation of a video to educate the parents, could be cost effective, accommodate caregivers with different levels of

reading abilities, language barriers and could be watched at the convenience of the caregiver. The “CPR Anytime Kit™” refers to a standardised video kit of BILS skills training that was given to 117 caregivers of preterm infants and children from 0 – 18 years before discharge (Knight, Wintch, Nichols, Arnolde & Schroeder, and 2013:9). The inclusion criteria include preterm infants who had a history of episodes of apnoea spells, bradycardia and infants with cardiac abnormalities (Knight et al., 2013:10).

In conclusion, the need for family-centred care and education for preterm infant’s caregivers in NNUs is discussed above (Bracht et al., 2013:115). BILS requires psychomotor skills, therefore mannequins are used to demonstrate to parents. Further, the utilisation of BILS video for BILS training could accommodate different levels of reading abilities and language barriers (Brannon et al., 2009:133).

2.5.2. Caregivers – health care professionals -Midwives

Midwives play an important role in preparing the parents of preterm infants before discharge as they are the ones who spend a large amount of time with the infants. According to Knight et al. (2013:9) a lack of time, discrepancy of nursing skills, variation in confidence levels and different instruction methods could prevent standardised BILS training to parents of preterm infants.

Brannon et al. (2009:134) state that a standardised self-instruction video (SIV) was produced by the American Heart Association. The (SIV) could also be watched prior to instructor-led BILS skills training as a supplemental learning tool. The BILS (SIV) was 30 minutes long and covered management of choking and airway obstruction as well (Brannon et al., 2009:34).

Furthermore, Jefferies (2014:34) states in the position statement of the Canadian Paediatric Society, that HCPs should provide education to the parents from admission to increase their knowledge and skills, increase their confidence levels and decrease stress. The pre-discharge training programme was reviewed by the Community Paediatrics Committee and by the College of Family Physicians of Canada to ensure good quality of the programme (Jefferies, 2014:31).

Group and individual sessions of BILS skills training and demonstrations of BILS skills can be provided by midwives to parents of preterm infants during their stay in hospital

(Judith, Gooding, Cooper, Arianna & Blaine, and 2011:25). Audio-visual material such as videos or DVDs should be provided, and medical information can be shared in layperson's terms to enhance retention of knowledge (Judith et al., 2011:23; Purdy, Craig & Zeanah, 2015: S24).

In an observational survey-based study performed at a quaternary academic paediatric hospital from June 2008 – December 2009, a second survey was conducted one year later after implementation of the BILS skills programme to determine nursing satisfaction (Knight et al., 2013: 9). The evidence revealed that the nursing satisfaction of the BILS training comfort levels were reported as confident, and knowledge and skills were moderate on telephonic surveys (Knight et al., 2013:9). One limitation of the study was that the researchers were unable to select a control population, as the BILS skills training was not standardised at the health care facility. Therefore, a descriptive observational design without a comparison group was conducted (Knight et al., 2013:15).

Further, the skilled health care professionals who introduced the programme to caregivers, who went through the checklist, compromised the generalisability of approach of the study (Knight et al., 2013:15). However, all the caregivers who watched the BILS skills training on the video were found to be competent and did not require remedial training (Knight et al., 2013:15).

Another limitation was that the longitudinal study posed unavoidable biases due to the numbers of caregivers who were contacted to participate in the telephonic survey, decreasing over time (Knight et al., 2013:15). According to Knight et al. (2013:15), the evidence revealed that more participants with prior BILS skills knowledge responded better than those without prior BILS skills, to the survey at six (6) months.

The "CPR Anytime Kit™" is an effective standardised self-instruction video kit method that is an alternative to instructor-led training in low-resource settings that provides BILS skills training to parents of preterm infants before discharge (Knight et al., 2013:14). However, Brannon et al. (2009:32) argue that preterm infants' parents watch an instructional BILS skills training video before instructor-led training, to ensure good retention of skills and to accommodate different education levels of the parents.

Brannon et al. (2009:38) also contend that video preparation is cost effective and the parents can watch it at a time most suitable for them. However, both the video and instructor-led training should be offered, as the video alone will not be effective (Brannon et al., 2009:38). According to Brannon et al. (2009:7) a limitation of the study design was that it simply compared “more training” with “less training.”

In conclusion most studies indicate the need for using multiple instruction methods during training. Further, there is a need to ensure that midwives are equipped and prepared to support parents of preterm infants with effective training before discharge.

2.5.3. Care givers- Healthcare professionals'-Doctors

Providing BILS training requires multidisciplinary support with more than just midwives. Parents of preterm infants could gain more from a multidisciplinary approach rather than a single approach from midwives. A cohort analytic study of family integrated care in a Canadian neonatal intensive care unit, where parents cared for their preterm infants, was designed by a multidisciplinary steering committee which consisted of physicians, nurses, parents, an educator, lactation consultant and social worker (Bracht et al., 2013:115). Parents were spending up to eight hours per day caring for their preterm infants whilst receiving daily education by healthcare professionals, and psychological support from parents who had a preterm infant before and had received health care in neonatal units (Bracht et al., 2013:115).

Knight et al. (2013:9) postulate that standardised BILS skills training is often compromised due to limited time, differences in nursing skills, instruction methods and health care professionals' HSPs confidence levels. In addition, BILS skills decline within one to six months after instructor-led training was provided to parents of preterm infants (Knight et al., 2013:9). Yet, according to Knight et al. (2013:14), the “CPR Anytime Kit™” is a flexible, sustainable method for parents of preterm infants to watch the video again after discharge to ensure BILS knowledge and skills retention of parents.

Knight et al. (2013:14) further argue that some doctors were concerned that BILS skills training to parents of preterm infants in the acute stage might cause anxiety, while the stress levels of these parents are already high. Therefore, resistance to implement the

video kit training at the institution where the study was done, ultimately affected the recruitment of participants (Knight et al., 2013:14).

However, Knight et al. (2013:14) further cited many studies (Dracup, Moser, Doering, & Guzy, 1997a; Dracup et al., 1997b, 1998; Moser et al., 1999; Schlessel et al., 1995, in Knight et al., 2013) where parents managed to learn BILS despite anxiety and that standardised BILS skills training is a high priority for families. Furthermore, written feedback from parents revealed that the BILS skills training significantly reduced their anxiety levels (Knight et al., 2013:14).

2.5 basic infant life support guidelines

2.5.4. American Heart Association (AHA) BILS 2010 guidelines

The AHA 2010 guidelines recommend that the historical sequence of Airway-Breathing-Compressions (ABC) be changed to Compressions-Airway-Breathing (CAB), to prevent a delay in “no blood flow” (Atkins, Berger, Duff, Gonzales, Hunt, Joyner, Meaney, Niles, Samson & Schexnayde, 2015: S520). The International Liaison Committee on Resuscitation (ILCOR) supported the change; they acknowledged that infants are prone to respiratory arrests (stop breathing) as ventilation, or artificial mask breathing, might be more important to commence resuscitation (Atkins et al., 2015: S520). Furthermore, animal and paediatric studies revealed that a combination of ventilation/breathing and compressions are more effective for respiratory arrests (Atkins et al., 2015: S520).

Manikin studies revealed that when BILS/CPR is started by one rescuer with 30 compressions, the delay in the first breath/ventilation is 18 seconds and when started with two rescuers, the delay is nine seconds (Atkins et al., 2015: S520). Due to limited data the Class IIb, Level of Evidence Consensus of expert opinion, recommended the CAB sequence to ensure that education and training with lay people, are done in a simplified manner and to ensure the retention of knowledge and skills (Atkins et al., 2015: S520).

Only topics reviewed are included in the 2015 American Heart Association Guidelines Update as part of a systematic review and it is recommended that the other

recommendations in the 2010 AHA Guidelines, remain the official guidelines (Atkins et al., 2015: S520).

The AHA and Emergency Cardiovascular Care (ECC) scientists' data from the Resuscitation Outcomes Consortium, a registry of 11 United States and Canadian emergency medical systems, revealed that from 2005 -2007, data for infants younger than 1 year, who had cardiac arrests after discharge and survived, were 3,3% and 9,1% for children 1-11 years old (Atkins et al., 2015: S520).

Five components to be observed to ensure effective compressions are: adequate rate, adequate depth of compressions, ensuring full chest recoil, fewer interruptions in chest compressions and preventing too much ventilation. Furthermore, to prevent complexity due to limited data, it is recommended that the chest compression rate of 100/minute increases to 120/minute for infants and children (Class IIa, LOE C-EO), (Atkins et al., 2015: S520).

The depth of the compressions must be one third of the anterior posterior diameter of the chest – 4 centimetres in infants and children. Two large observational studies examining data from a Japanese national registry of paediatric OHCA revealed that Compression-Only CPR for infants, who had a respiratory arrest, is not better than for patients who did not receive basic life support (Atkins, et al., 2015: S522).

The 2015 recommendations are that, since most infants are having respiratory arrests the conventional method of breathing and compressions, is recommended. Compressions-only is recommended if an infant has a cardiac arrest and the lay person is unable or unwilling to give breaths (Atkins, et al., 2015: S522).

2.5.5. Resuscitation council (UK) guidelines 2015 - pediatric basic infant life support

The 2015 International Liaison Committee on Resuscitation (ILCOR) Consensus on Cardiopulmonary Resuscitation and Emergency Cardiovascular Care Science with Treatment Recommendations were included. Stakeholders who participated in the process included members of the public and cardiac arrest survivors. Information of the guidelines development process is available on the website of (ILCOR).

A peer review of the Resuscitation Council (UK) Guideline was done by the Executive Committee of the Resuscitation Council (UK), which includes lay people and the key stakeholder groups (Maconochie, Bingham & Skellett, 2015:1). The National Institute of Health and Care Excellence accredited the process to compile the Resuscitation Council (UK) Guidelines 2015 - Paediatric basic infant life support (Maconochie et al., 2015:1).

The guidelines can be used by healthcare professionals and lay people. The ILCOR (2015) review of resuscitation included in these guidelines assist with teaching, is simplified for lay people to ensure retention of knowledge and skills (Maconochie et al., 2015:1).

A limitation is that, due to a lack of evidence and randomised trials on paediatric life support, observational studies and national and international registries were used to collate valuable data (Maconochie et al., 2015:1). Infants and children are mostly having cardiorespiratory arrests due to secondary causes such as difficulty in breathing or respiratory arrests, therefore the resuscitation sequence Airway-Breathing-and Circulation (ABC) is recommended (Maconochie et al., 2015:1).

2.5.6. Helping babies breathe (HBB)

The HBB programme was developed by the American Academy of Pediatrics in 2011. The HBB programme has a step-by-step guideline for policy makers, programme managers, master trainers, facilitators all users to implement the HBB neonatal resuscitation programme. The guidelines have a framework to implement a sustainable HBB programme, which consists of the following: a national plan to develop policies and guidelines for strategic planning to ensure the right to use the programme and fairness, availing a budget for preparation of training and obtaining equipment such as mannequins, finding master trainers and developing training plans capacity building, continuous mentoring; supervision and self-assessment, monitoring and evaluation of the programme, capturing of statistics and lastly quality assurance by including regulations, operational guidelines and compliance (AAP, 2011:6).

A recommendation is that The National Health Authorities should perform a situational analysis to allocate a budget for the programme at national, provincial and district level (AAP, 2011:6). The course content can be adapted by facilitators to accommodate

the health care system, culture and environment. However, the basic steps will always remain the same (AAP, 2011:6). All stakeholders such as the Minister of Health, public and private health multi-disciplinary teams, community leaders, donors, academics from universities and colleges, the public and media should be involved right from the start to ensure the sustainability of the programme (AAP, 2011:7).

2.5.7. Western Cape Department of Health 2030 Healthcare goals

The purpose of the Western Cape Department of Health's (WCDOH) transformation strategy is to improve the health of the people that it serves. The improvement must be person-centred to reflect from quantitative (measurable) to qualitative reduction of infant mortality rate (WCDOH, 2017:1-2). The infant mortality reduction rate is a priority of the (WCDOH) 2030 Healthcare goals.

2.6. Conclusion

The findings of the literature review highlighted BILS training and the need to equip parents of preterm infants with BILS skills training before discharge home, to save their infants' lives when they stop breathing at home. Evidence from literature reviewed, provided statistics about infant mortality rates, globally, nationally and provincially. Preventable leading causes of preterm infant deaths included prematurity. The various international BILS guidelines are also discussed.

Therefore, a well-planned pre-discharge education plan for parents of preterm infants was discussed to educate parents on BILS training and preventative strategies. Recommendations made in articles reviewed were to equip caregivers/parents and families with necessary knowledge and skills to save preterm infants lives, and to ensure a person-centred approach, as envisaged by the Western Cape Department of Health 2030 healthcare goals.

The inadequate, or lack of, BILS skills training for parents of preterm infants before discharge, has led to the increase of infant mortality post discharge. Therefore, the need to equip parents of preterm infants with basic life support skills before discharge, is paramount. A need for research on the topic has been identified due to a lack of current evidence of perspectives of preterm infants' caregivers on the BILS skills training before discharge.

The next chapter will focus on the research methodology used to explore the perspectives of caregivers regarding the BILS training provided before discharge. The research design and methods utilised in the study will be elaborated upon.

3. CHAPTER THREE

RESEARCH METHODOLOGY

3.1. Introduction

This chapter identifies the research methodology used in the study. Further, the research design, data collection methods, data collection tool, ethical considerations and trustworthiness of the data are discussed. While the data analysis methods are discussed in this chapter, the findings of the study will be described in chapter four. The literature which was reviewed in the previous chapter will be reviewed with considerations of the findings, in chapter five where recommendations and conclusions will be highlighted.

3.2. Research approach

The methodology utilised in this study was a qualitative descriptive study with a case study approach. A qualitative research is a methodical subjective approach used to describe life perspectives and give meaning to data provided by participants (Rule & John, 2011:60; Burns & Grove, 2011:73). Qualitative research approaches which are used in research include; phenomenological, grounded theory, ethnographic, historical research and the exploratory-descriptive qualitative research and case study approach (Grove et al., 2015:68).

Grove et al., (2015:68) further suggest that the qualitative researcher describes the perspectives of the phenomena. In this study the researcher explored in-depth the perspectives of the caregivers on the BILS skills training, as the participants have their own special or unique perspectives, in view of time and context, to provide a holistic picture.

The single case study approach that was utilised, described an in-depth understanding of the perspectives of the parents and HCPs of preterm infants on the BILS training before discharge, at the Public Secondary Hospital (Grove et al., 2015:136). These parents and HCPs shared their individual perspectives of their perspectives on the phenomenon (Grove et al., 2015:136).

Perspectives are multiple, constructed realities; the knower and known cannot be divided, therefore knowledge is co-constructed; interviews are value bound and all

simplifications are bounded by time and context (Burns & Grove, 2011:23). The case study approach aspired to generate new theory in this case study, by applying inductive reasoning. (Rule & John, 2011:98). Knowledge is co-constructed when the researcher set aside her pre-existing assumptions and viewed the phenomenon as it was perceived by the participants and described it in-depth (Rule & John, 2011:98).

Therefore, this descriptive single case study approach described the perspectives of caregivers of preterm infants on the BILS Skills training before discharge at the secondary hospital best in their natural setting (Rule & John, 2011:60).

The purpose of the study was to explore the perspectives of the caregivers on the pre-discharge BILS skills training for parents of preterm infants at Mowbray Maternity Hospital, a public hospital in the Cape Town Metropole, in the Western Cape South Africa.

3.3. Study setting

In South Africa, healthcare is governed at National, Provincial and District or Regional level. The Western Cape Province is one of nine Provinces. Western Cape Health Care consists of districts, which have primary care facilities such as clinics, community health care centres and Midwife Obstetric Units (MOUs) (Republic of South Africa, 2015). Secondary care services are provided by district hospitals and regional hospitals in the Western Cape. The Secondary Hospital where the study was conducted is a regional hospital within the Metro West District Health Services, with many referrals from five (5) busy Midwife Obstetric Units (MOU's) and low risk patients residing within the catchment area of the hospital as depicted in figure 3.1 below (Republic of South Africa, 2015).

At the MOUs, registered midwives provide low risk antenatal, intrapartum and postnatal care to women who are living within the community or catchment area of the MOU. High-risk women with conditions such as hypertensive disorders, preterm labour and any obstetric emergencies are referred to a secondary level of care hospital (Republic of South Africa, 2015).

These preterm or high-risk infants are transferred in-utero, or after they are born, to the hospital from one of five Midwife Obstetric Units (MOUs) and one district hospital from different communities. Low risk infants also receive care at the secondary

hospital referred to previously, due to them residing within the catchment area (Republic of South Africa, 2015). However, the BILS skills training is only being given to parents of preterm infants and high-risk term infants at Mowbray Maternity Hospital.

Specialised neonatal care and discharge planning are provided to the preterm infants in a seventy-three-bedded neonatal unit at the Secondary Hospital by different categories of doctors. The medical team consists of three consultants, seven career medical officers, two community outreach career medical officers, four community service doctors, two rotating registrars and one rotating intern (Van Niekerk, 2018).

Metro West

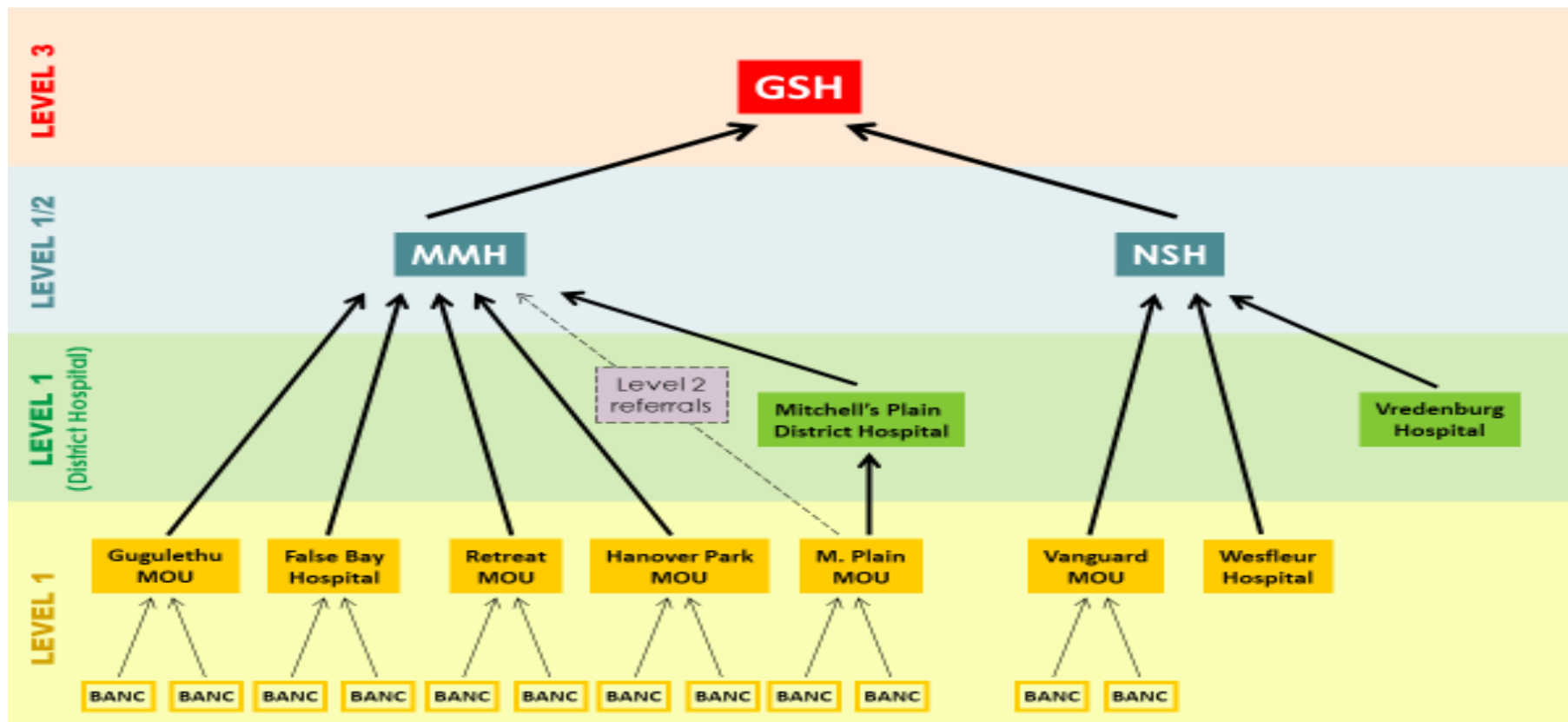


Figure 3.1: Metro West District Health Services (Moore, 2018)

A nursing manager described the nursing team in the neonatal unit consists of one assistant manager, two operational managers, eight advanced midwives, eight basic midwives, two staff nurses and eight registered assistant nurses on day duty. The same number of nurses and midwives are on night duty. BILS skills' training is only provided on day duty to caregivers (Booys, 2018).

At the high-risk clinic of the Secondary Hospital, discharged preterm infants are followed up for their 18 – 20 weeks corrective age neurological development assessments. A Neonatologist described the multi-disciplinary team providing care at the high-risk clinic consists of two consultants, one registrar, one midwife, one speech therapist and one physiotherapist (Van Niekerk, 2018).

3.4. Research design

A research design is a blueprint, or plan, for conducting a study (Grove et al., 2015:211). This study focused on a type 2 single case study approach to discuss the phenomena of interest within a bounded context such as people, an institution, and a programme (Rule & John, 2011:3). A case study is created due to it being singular and distinct (Rule & John, 2011:3). The phenomenon on the perspectives of caregivers of preterm infants regarding the BILS skills training, before discharge, at a public secondary hospital in the Cape Metropole in the Western Cape, South Africa, was explored.

A qualitative, single descriptive case study methodology was utilized for this study. A single case study is a comprehensive study of a group of people such as the caregivers, a programme or an institution to get an in-depth analysis of the perspectives of all the role players about the BILS skills training at the secondary hospital (Rule & John, 2011:61; Brink, Van Der Walt & Van Rensburg, 2008:110).

Grove et al. (2015:11) and Rule and John (2011:61) confirm that a case study is an in-depth analysis and systematic explanation of a patient, or a homogeneous group of patients, such as the caregivers of preterm infants in their natural setting to enhance understanding of health care interventions.

Theory in case studies is used to test, or apply, theory (Rule & John, 2011:91). However, there is a risk that the theory might not fit into the case study. This could result in establishing new, or revising existing, theory. Because the case study could

also generate new theory, the researcher used the case to generate new theoretical perspectives of the caregivers on the BILS training.

The single case study was chosen for this study as it was carried out to describe the phenomenon in-depth and currently this was the only context within which the perspectives of the caregivers of preterm infants about the BILS training, were explored (Yin, 2014: 51 - 52).

Yin, (2014: 50) contends that the unit of analysis is the source of information such as the different caregivers, who are the parents, or guardians of the preterm infants, and HCPs, such as doctors and midwives. As shown in the figure 3.2 below, a single case study with embedded units of analysis was used with multiple methods to explore the perspectives of caregivers of preterm infants on BILS training.

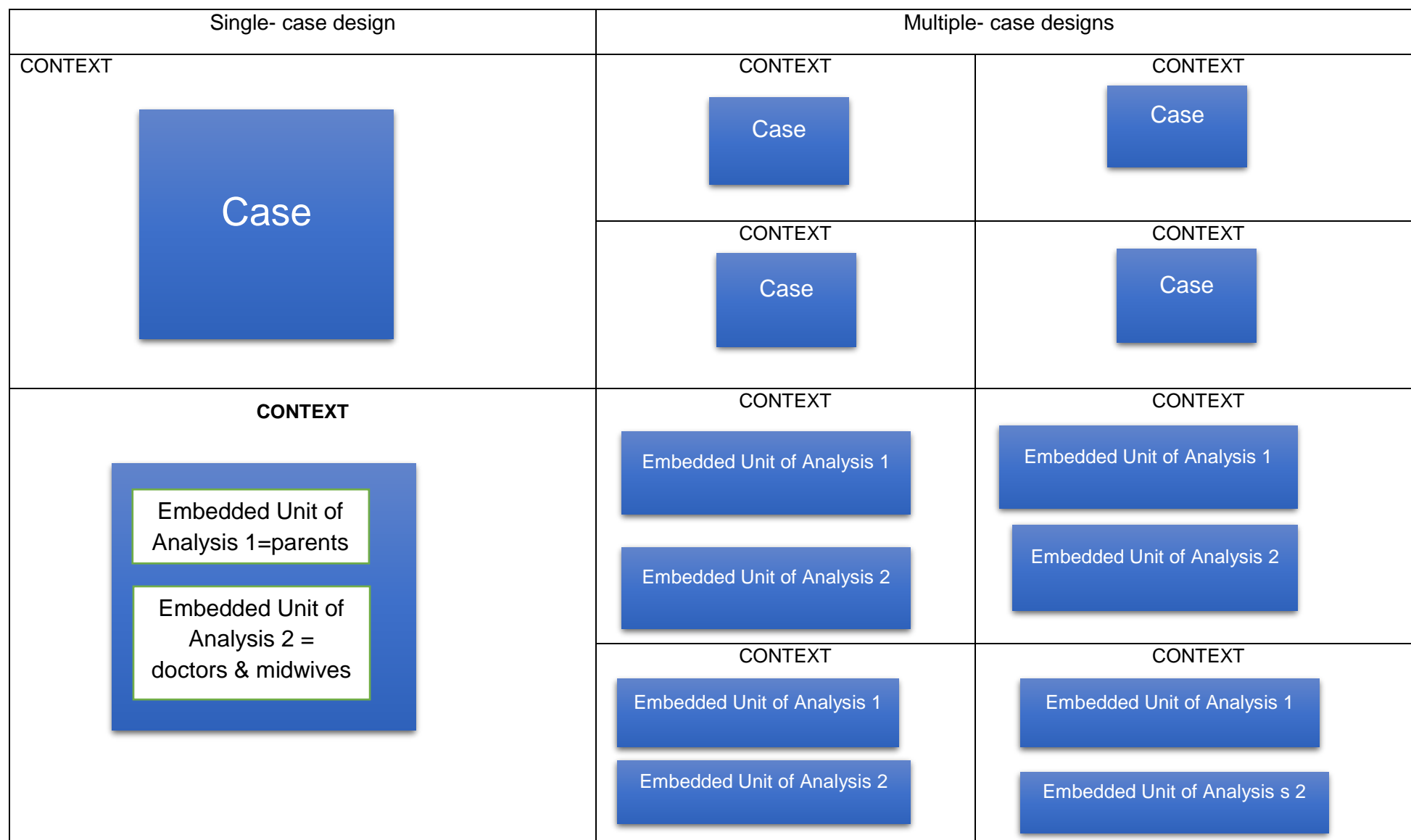


Figure 3.1: Types of case study design (Yin, 2014)

3.5. Population and sampling

A population refers to the entire group of individuals, such as the caregivers at an institution, the secondary hospital, who were involved in an event with common defining characteristics such as the BILS training programme (Polit & Beck, 2014:51; Grove et al., 2015:509).

The population for this study, then, was parents of preterm or low birth weight infants who received BILS training before discharge and health care professionals who were involved in the BILS training at the secondary hospital in Cape Town, South Africa. Statistics obtained from the BILS skills training register at the hospital revealed that 220 caregivers (parents or guardians) received BILS skills training from January 2017 to December 2017 (MMH, 2017). Statistics obtained from the training statistics at the hospital revealed a total of 11 doctors and a total of 25 midwives received valid basic infant life support training during the last two years (MMH, 2018).

A sample is a subgroup of the population from which the researcher collected the data (Polit & Beck, 2014:51; Grove, Gray & Burns, 2015:511). Purposive sampling refers to intentionally selecting people, or participants, who have insight about the case and could therefore provide their in-depth perspectives of the BILS skills training to parents of preterm infants, before discharge (Rule & John, 2011:64).

The parents who received BILS training before discharge were a purposive sample consisting of parents of preterm or low birth weight infants (LBW) who were discharged from the public hospital 18 or 22 weeks prior to the time of data collection. These four parents received BILS skills training before discharge. The HCPs, who were involved in the BILS training, were a purposive sample which consisted of four doctors and nine midwives.

3.5.1. Inclusion criteria

Only parents who received BILS skills training, doctors and midwives who were involved with the preterm or low birth weight infants discharge planning from the secondary level hospital, were included in the study. The parents of the preterm or low birth weight infants who followed up at the 18- and 20-weeks' neurodevelopment assessment clinic at the Public Secondary Hospital, were included in the study.

Only permanently employed neonatal doctors and midwives who were involved with the discharge planning of the preterm infants or involved in the BILS skills training to caregivers before discharge, at the Secondary Hospital, were included in the study.

3.5.2. Exclusion criteria

All parents of preterm, low birth weight infants and term infants who did not receive the BILS training before discharge, at the Public Secondary Hospital were excluded. All doctors and midwives who were not employed at the hospital, not involved in the pre-discharge planning of the preterm infants and BILS training at the hospital, were excluded.

3.6. Data collection process

3.6.1. Approval obtained

Ethical approval was obtained from the Human Ethics and Research Committee at Stellenbosch University on the 09th May 2018 (approval HREC Reference #: S 18/02/030.) Once approval from the Human Ethics and Research Committee at Stellenbosch University was granted, the researcher requested permission from the Western Cape Department of Health to conduct the study. (Approval obtained 03 July 2018, Reference: WC_201805_034).

The researcher requested Institutional permission from the Chief Executive Officer, Deputy Manager Nursing, and the Head of the Neonatology to have access to the participants and to conduct the study at the Public Secondary Hospital. Permission to conduct the study at the hospital was obtained on the 23rd July 2018, via email but a formal letter was received on the 26th July 2018.

3.6.2. Recruitment

Once ethical approval, permission from WCDoH and institutional permission were obtained the researcher started the recruitment. The researcher arranged with the Head of Neonatology to have access to the parents at the high-risk neurological development clinic and the doctors in the NNU. Furthermore, the researcher arranged with the doctor and midwife, who are working at the high-risk clinic, that the researcher obtain informed written consent from the caregivers to conduct the in-dept individual interviews.

Voluntary informed written consent was obtained from each parent individually on the day that they attended the high-risk neurological development clinic at the Secondary Hospital. All five participants were individually informed that they could refuse to participate and could withdraw at any stage of the interview without an explanation. Interviews with the parents who received the BILS training before discharge, were done in a simplified manner in a private room near the clinic after they were seen by the doctor at the clinic.

The researcher also arranged with the Head of Neonatology to have access to the doctors in the NNU. Voluntary informed written consent was obtained by the researcher from the doctors' days in advance before the interviews took place, to determine a suitable time and venue for participants to be interviewed. However, voluntary written informed consent was taken from participant doctor one at 10h00 and he was interviewed at 14h00 on the same day, as it was the most suitable time for the participant. The researcher scheduled with the other three doctors individually on a day that suited each one.

The researcher arranged with the Head of Nursing to have access to the midwives. The operational and assistant manager of the NNU accommodated the researcher to obtain individual informed written consent from the midwives in the NNU, who provided the BILS training to the caregivers, days before the focus group discussion was conducted, as it was determined by the most suitable time for everyone.

A "do not disturb" sign was posted on the door during interviews to prevent any interruptions. Individual appointments were made with the midwives and doctors to ensure the interviews were done in a private room at a time that suited them. Semi-structured (open-ended questions with probes were used during the in-depth interviews and was recorded on two audio-recorders whilst field notes were taken by the researcher.

The researcher, who holds a Postgraduate Diploma in Advanced Midwifery and Neonatal Nursing Science, collected the data. She is currently working as a Clinical Programme Co-ordinator: Education at the Public Secondary hospital where she has been employed for 23 years. The researcher was one of the key role players in the re-implementation of the BILS training in 2009 at the Public Secondary Hospital. The

researcher also initially provided the BILS training from 2009 – 2012 to the parents in the KMC ward.

3.6.3. *Data collection tool- interview guide*

The semi-structured interview guides for the caregivers were available in English, Afrikaans and isiXhosa. The researcher arranged with an isiXhosa interviewer to interview isiXhosa speaking participants who were unable to communicate in English or Afrikaans. However, all the participants preferred to be interviewed in English.

English was the second language of all four parents who received the BILS training before discharge at the hospital. They alluded that they received the BILS training in English and preferred to be interviewed in English. English were the first language of four doctors, six midwives and the second language of the remaining three midwives. The HCPs preferred to be interviewed in English as it is the medium most frequently used for HCPs at the hospital.

The semi-structured interviews ensured that the researcher posed a fixed set of conversational questions to the participant, allowing no fixed answers (Grove et al., 2015:512). Simplified semi-structured questions were compiled for the individual parents of preterm or low birth weight infants who had BILS Skills training to accommodate all educational levels. The researcher ensured that the first introductory question was “tell me more about yourself” to build a rapport with the participants and to get demographic information from the clients.

The researcher also probed for more information when required. The researcher probed, saying “tell me more about...” Yin (1994:80-81) states that the type of research questions normally entails open ended questions such as “how” and “when.” Furthermore, the case study provided descriptive information about the contributing factors of an event, thus describing the “why” and “what” (Rule & John, 2011:62; Brink et al., 2008:110).

The researcher utilised the semi-structured interviews during interviews conducted for data collection. The semi-structured interview guides were used for the different categories of caregivers, such as parents who received the BILS training and the healthcare professionals who were involved in the BILS training.

The statement “Let’s talk about the BILS skills training offered to caregivers of preterm infants at this hospital,” allowed the parents to share their perspectives of the BILS training. Probes such as “tell me more about...,” ensured that the caregivers shared their perspectives about the BILS training in-depth. The interview guides are attached as Appendix 5, 6 and 7.

3.6.4. Pilot interviews

The value of the pilot study was to develop, test and refine the planned research questions and procedures that were used in the official case study; however, data collated during the first pilot interview was not re-used (Yin, 2014:240).

The interview guides were perused by the study supervisor and the researcher during a meeting, days before the pilot interview was conducted. Rule & John (2011:65) advocate that the initial research questions should be obtained from the main research questions “to initiate discussions”. The interview guides were discussed by the researcher and the supervisor and a need was identified to review the interview guides to align them with the research questions as reflected in appendix one, two and three.

The statement was re-constructed from “Tell me what you remember about the basic infant life support training” to “Let us talk about the basic infant life support training you received before your infant/baby went home.” The statements were restructured to open ended questions that are posed in a conversational manner. The revised sentences accommodated educational levels of all participants (Rule & John, 2011:65).

The first pilot interview was scheduled at the secondary hospital on the 24th July 2018. Individual informed written consent was obtained at the high-risk unit from a coloured female parent, who brought her infant for the 18 weeks neurological development assessment. The researcher arranged that the individual pilot interview take place after the parent was seen by the doctor at the clinic. However, the parent withdrew from the study after she was seen by the doctor as her husband needed to go back to work.

Informed written consent was obtained from a female parent who met the inclusion criteria at the high-risk clinic on the same day. The study supervisor was with the researcher during the pilot interview to assess and evaluate the researcher’s interview

skills in a private room near the high-risk clinic. The interview was audio- recorded on two devices to prevent equipment failure.

The researcher and study supervisor reflected on the pilot interview a few minutes after it was conducted. After detailed reflection and discussion of the pilot interview the researcher and study supervisor, agreement was reached that the researcher needed to refine her interview skills. Pilot interview one was not included in the study, as the research questions were not answered, and the researcher needed to refine her interview skills (Yin, 2014:96).

The researcher received training from the supervisor who facilitated demonstrations with the researcher to ensure that the researcher mastered interviewing skills and focus group interview skills before the next pilot interview. According to Yin (2014:96), “a Pilot interview is not a Pre-test.” However, the pilot interview assisted the researcher to improve her interview skills (Yin, 2014:96). The interview guides were not reviewed after the pilot interview, as they addressed all the research questions in a simplified manner.

A third pilot interview with a parent who received the BILS training was arranged due to the other two pilot interviews being discarded. Individual informed written consent was obtained, the individual in-depth semi-structured interview took place while the parent was waiting to be seen at the high-risk clinic in the private room near the clinic. The research questions were answered during this interview. The interview lasted thirty minutes and twenty-six seconds.

The scope of the pilot interview is to provide an opportunity to address significant basic issues and methodological issues (Yin, 2014:97). The researcher did not identify any methodological issues during the final pilot interview. The lesson learned about the field procedures or basic issues (from the participant who withdrew from the pilot interview) was that parents might want to leave as soon as they have been seen at the high-risk clinic.

Therefore, the researcher arranged with the doctor and midwife at the clinic to interview the caregivers while they are waiting at the clinic to be seen by the doctor. An agreement was reached, and the researcher interviewed the parents as soon as informed written consent was received in a private room near the clinic. The

researcher ensured that she did not cause any inconvenience to the routine operations or functioning of the high-risk clinic (Yin, 2014:98).

3.7. Data collection methods

Data collection methods are the pre-established plan or proposal of collecting information/data from the study subjects (Rule & John, 2011:63; Brink et al., 2008:54). Burns & Gray (2011:85) and Rule & John (2011:63) suggest that the researcher consider the multiple aspects that affected the specific case study and include this vital information when the data collection and analysis process was planned.

The researcher applied triangulation and utilised three data collection data sources in the case study (Rule & John, 2011:63; Grove et al., 2015:513). A single case study with multiple units of analysis was chosen for this qualitative study, as it is assisted in providing a descriptive understanding. Multiple sources of information, such as individual interviews and focus groups discussions, were used for a wide collection of information needed and provided an in-depth picture (Yin, 2014:119).

According to Yin (2014: 118-119), a single source of evidence such as only individual in-depth interviews with parents who received the BILS training, was not recommended for case studies as it poses concerns of quality of the study. Therefore, multiple sources, such as in-depth individual interviews with the parents and doctors, were included. Furthermore, two in-depth focus group discussions with the midwives about the pre-discharge BILS skills training sessions to parents of preterm infants, were held to ensure overall quality of the study (Yin, 2014:119; Burns & Grove, 2011:513).

The use of multiple sources of evidence such as the perspectives of caregivers, doctors and midwives, of the pre-discharge BILS skills training sessions to parents of preterm infants increased the confidence that the study was done thoroughly (Rule & John, 2011:64). The “relativist” orientation added value to the possibility of multiple realities of the participants’ perspectives on the BILS training to parents of preterm infants pre-discharge, accurately (Yin, 2014:122; Rule & John, 2011:64).

3.7.1. Individual interviews

In-depth semi-structured interviews guides were compiled to enhance the conversation between the researcher and the parents who received the BILS training pre-discharge, and midwives and doctors who were involved in the BILS training (Yin, 2014:212; Rule & John, 2011:65; Grove et al., 2015:506).

After the pilot study, arrangements were made with the Acting Operational Manager of the Neonatal Unit to go and obtain individual informed written consent with the midwives who are providing the BILS skills training in the NNU. The researcher obtained written informed consent from the one midwife who was providing the BILS training. The Neonatal unit was quite busy on the chosen morning; therefore, the individual interview was scheduled with the midwife for 14h00 the same day.

The researcher ensured that she was prepared for the interviews, applied her interpersonal skills and ensured effective communication at the level of her participants (Rule & John, 2011:64). Further, Rule and John (2011:64) contend that to ensure good interviews are conducted, the researcher needed to initiate a relaxed atmosphere. The researcher invited the participants into the quiet well-ventilated clean room in a courteous manner. She offered them a seat and to ensured that they felt comfortable before and during the interview.

She explained to them that the purpose of the interviews was to obtain their perspectives on the BILS training they received as parents or were involved with as HCPs. Furthermore, she explained that it will be more a discussion to obtain their perspectives and that they must feel free to stop or ask that information be clarified. The participants were asked if they were ready to start the interview.

The participants were informed that the researcher will be audio recording the discussions on two devices to ensure that all the information is kept safely for the study. She reassured them that their confidentiality and privacy will be protected and that they could withdraw from the study at any stage without any consequences.

The researcher commenced the interview in a conversational manner rather than an interviewing manner to build rapport. She started with the least serious or demanding questions such as “tell me a bit more about yourself.” The researcher listened to the participants, nodding her head, observed for non-verbal communication and avoided

interrupting. Furthermore, the researcher was respectful and sensitive to the feelings of the participants. Lastly the researcher probed, clarified and summarised information shared by the participants.

The researcher reported any preliminary findings and contradictory evidence such as participant bias acquired during the data collection process, to her study supervisor for alternative explanations and suggestions to reduce bias. The role of the research supervisor was to oversee the whole study and provide interview skills, guidance and support to the researcher. The supervisor has extensive interviewing skills.

Furthermore, the researcher adhered to the highest research ethics standards by avoiding plagiarism and misrepresenting information (Yin, 2014:76). The researcher is fluent in Afrikaans and English. The researcher planned for a Xhosa speaking interpreter to do the interviews with the patients fluent in Xhosa, who did not speak English or Afrikaans fluently.

The Xhosa interpreter has an Honours Degree in Advanced Midwifery and Neonatal Nursing Science. She is currently working at the secondary hospital as a Clinical facilitator and was not called to interpret during interviews with participants in isiXhosa as all the participants preferred to be interviewed in English.

The isiXhosa speaking interpreter received intensive training about the study protocol, from the researcher before the data collection commenced, to ensure good quality of data. Furthermore, the researcher ensured that the isiXhosa interpreter agreed and signed a clause in the consent form that she will abide with the anonymity and confidentiality clause.

Caregivers who became distressed or emotional when perspectives were shared would have been referred for counselling to the two social workers on the premises of the secondary hospital. Arrangements were made with the social workers prior to the data collection sessions, to ensure that that they were available if participants needed counselling. However, none of the participants needed counselling. Interviews were done in a non-judgemental manner and the researcher respected the perspectives of the participants.

The researcher planned with the doctor and midwife, who work at the high-risk neurological development follow-up clinic, to recruit and interview parents of preterm

or low birth weight infants who had the BILS training once a week. The sample consisted of five parents who received the BILS training before discharge at the secondary hospital.

An agreement between the researcher, midwife and doctor, who consult with parents at the high-risk neurological developmental clinic, was reached that the researcher would interview these parents before consultation. An average of one parent met the inclusion criteria per day. Four parents were Xhosa and one was a coloured parent. Normally all races are receiving perinatal care at the hospital, however no white and Indian parents who met the inclusion criteria were at the clinic during the time of recruitment for data collection. This provided diversity of cultures, different races, and languages such as Afrikaans, English, isiXhosa and different educational levels.

The researcher purposively sampled four doctors who are employed at the secondary hospital and who have been involved in the BILS skills training. These doctors were individually interviewed by the researcher until saturation was determined. All the doctors who were interviewed were involved in the pre-discharge planning of the preterm infants from the Public Secondary Hospital. One doctor is employed at the secondary hospital, and in addition does outreach at the high-risk infant follow-up clinics in five communities, where she has seen parents who received BILS training at the high-risk follow-up clinic with their infants.

The audio recordings and the transcripts of two pilot interviews were assessed and evaluated by the study supervisor. The study supervisor provided feedback that the interview skills of the researcher has improved. Interview two with the midwife and interview three with the parent who received the BILS training, were included in the findings of the study.

3.7.2. Focus groups

The purpose of the focus group discussions was for the researcher to interview and discuss with the midwives, who were involved in pre-discharge planning of BILS skills training, to obtain the in-depth multifactorial perspectives of these midwives about the BILS training at the hospital (Rule & John, 2011:66).

Two focus group discussions (FGDs) were conducted with four midwives at a time. The researcher conducted the FGDs in a conversational manner to obtain the

perspectives of the midwives about the BILS skills training. However, “mutual or subtle influence” between the researcher and interviewees, called “reflexivity” was prevented to ensure a true reflection of the focus group interviews (Yin, 2014:112).

The first focus group comprised the managers which included; three Operational Managers and one Assistant Manager involved in pre-discharge planning of preterm infants. One Operational Manager also provided BILS training to parents of preterm infants and midwives.

The researcher separated the midwives according to their status to ensure a safe environment for the participants to enable them to freely discuss their perspectives and perspectives on the BILS skills training to parents of preterm infant’s pre-discharge.

3.7.2.1. Focus group one

Focus group one discussion was conducted on the 14th August 2018, with the four midwives who are involved in the BILS training programme in a managerial capacity. The focus group discussion was conducted in a private spacious room in the management suite after a managers’ meeting. The midwives were only available between 11h00 – 12h30 on the day the focus group discussion was scheduled as they needed to attend another two meetings after the focus group discussion.

Despite one accidental interruption, the privacy and confidentiality of the participants were not compromised, as the participant who was busy talking stopped talking. The discussion resumed fluently after the interruption. The focus group discussion lasted fifty minutes and nineteen seconds.

3.7.2.2. Focus group two

The focus group two discussion was conducted on the 5th September 2018 in the spacious skills laboratory of the hospital. The focus group consisted of four midwives who provided the BILS training, including the clinical facilitator who also provides BILS training to newly qualified midwives.

The two focus groups consisted of a minimum of four participants per group. Data saturation was reached once all the key research questions were answered and no new information on the perspectives of all the caregivers on the BILS training was obtained (Rule & John, 2011:72).

Despite an accidental interruption for urgent equipment, the focus group discussion resumed fluently and without further interruptions. The four participants continued to share their perspectives on the BILS training light-heartedly. The focus group discussion lasted fifty-six minutes and forty-seven seconds.

The researcher strictly adhered to the research protocol and understood the purpose of the case study. Therefore, protocol issues were understood by the researcher to make analytic judgements throughout the data collection phase (Yin, 2014:76-77). Bracketing of priori issues was done, which means that the researcher's capability to discard her preconceived ideas, existing knowledge and individual biases about the BILS skill training prevented interference with the study (Yin, 2014:76-77).

3.7.2.3. Field notes

Yin, (2014:124) refers to field notes as any hand-written notes in the researcher's diary, electronically captured information, audio recordings and observation taken during interviews. The researcher kept a reflective journal on all the interviews and made notes about observations of facial expressions or body language during the interviews. All notes were unorganised initially, but the researcher ensured that data was efficiently documented and stored to retrieve it at a later stage (Yin, 2014:24).

The researcher strove to be well informed about the phenomenon, to meet the requirement, "able to manage unexpected issues in data collection; asked good questions; being a good listener, have adaptability and flexibility when needed" (Yin, 2014:73-74).

3.8. Data analysis

3.8.1. *Interpreting the case*

Burns & Grove (2011:93) argue that qualitative data analysis occurs simultaneously with data collection. The researcher realised during data analysis that it is a creative and intellectual process where she needed to work with the data collected to find patterns of meaning (Rule & John, 2011:75).

The researcher kept a reflective diary as she reflected after each interview and focus group discussion during the data collection process. The researcher utilised the research question and objectives as a “guiding force”, which means guidance to ensure the research question is answered during the data analysis process (Rule & John, 2011:75).

Rule & John, (2011:75) contend that interpretation of the descriptive single case study is obtained through data analysis, a process of exertion of the data to find patterns and meaning. Data analysis is a crucial stage of the research process when the researcher constructed thick descriptions, identified themes, and theorised the case study. The data analysis method of Rule & John was used for this study.

3.8.2. *Organizing and preparation of the data*

The semi-structure in-depth interviews and FGDs data was managed shortly after each data collection session, while all the details could still be remembered. The audio recordings of the interviews were sent to the transcriber ASAP to ensure increasing volumes of data are simultaneously captured and stored in an organised manner. Compilation of the case study database was done electronically. Accurate recordkeeping was done to ensure order and a system for the researcher to access data for data analysis and to keep an audit trail (Rule & John, 2011:75).

3.8.3. *Transcription of interviews*

Transcribing of the audio recordings of each interview was done as soon as possible after an interview by an outsourced transcriber. The transcriber had to complete a confidentiality agreement. Once the transcripts were received by the researcher, the researcher listened to the audio recordings and checked the recording against the

transcript to ensure that the recording was transcribed verbatim. This enabled and the researcher to familiarise herself with the information (Burns & Grove, 2011:93).

The verbatim (“word by word”) transcribing used symbols, such as dashes (-) to indicate pauses, and ellipses (...) to indicate gaps and prolonged pauses. All non-verbal communications such as laughter, crying was included in the text in square brackets (Burns & Grove, 2011:93). Once the transcripts were checked for quality the researcher made corrections, cleaned the transcripts and mostly attended to grammar to ensure the authenticity of the transcript (Rule & John, 2011:77).

3.8.4. *Immersion with the data*

During immersion of data, the researcher described all the audio recordings, observations of non-verbal communication, and journal reflections of the setting. The researcher read written notes, listened to audio recordings for emphasis and feelings. The data analysis commenced by documenting initial impressions and discussing the data with the supervisor (Burns & Grove, 2011:94; Yin, 2014:126).

3.8.5. *Coding interview transcripts*

Coding is a process in data analysis where the researcher highlighted and assigned different labels to different parts of the interview transcripts which captured the perspectives of caregivers on the BILS training. The researcher needed to immerse herself in the data by listening to the recordings several times and read and re-read the transcripts which resulted in coding and recoding (Rule & John, 2011:77).

Codes which hold significance to the objectives of the case study, were assigned to data in the interviews. Coding is a fundamental part of data analysis, as the researcher needed to make intellectual, analytic and methodological decisions that affected the entire analytical process (Rule & John, 2011:77).

Yin (2014:127-128) argues a chain of evidence or coding must be produced, thus the researcher ensured the following:

- ✚ All relevant sources used such as written notes, interviews or observations were referenced.
- ✚ Evidence such as key phrases or words in documents, was highlighted in yellow.
- ✚ The dates and times of interviews were stipulated.

- ✚ Circumstances of data collections were consistent with the case study protocol.
- ✚ The link between the interview guides questions and original study question were reviewed by the study supervisor and researcher.

3.8.6. Content analysis

Once the coding was completed the researcher started with content analysis of the interview transcripts. The codes were scrutinised to recognise “Patterns such as similarities, differences and code absence, referred to as absence of coded data in certain interview transcripts” (Rule & John, 2011:78).

3.8.6.1. Logical grouping of codes into categories

Similar codes were grouped logically into categories, which were given a name. Further analysis of categories resulted in creating sub-themes. Sub-themes were clustered into main themes. The process of working with codes to themes is common in case study research, which highlights the importance of content analysis (Rule & John, 2011:78).

Quotations of raw data from the interview transcripts were used to substantiate the “relationship between the themes and data to provide a blend of “the real” and the abstract” (Rule & John, 2011:77). Data analysis and interpretation are serious stages in research, which granted the researcher an opportunity to construct thick descriptions, to identify themes, obtain explanations of perspectives of the caregivers in the case study (Rule & John, 2011:75).

3.8.6.2. Theorising the case study

Theory in case studies is used to test or apply theory. However, there was a risk that the theory might not fit into the case. This could result in establishing or revising existing theory (Rule & John, 2011:98). For this reason, the researcher used the case to generate new theoretical perspectives of the caregivers on the BILS training, pre-discharge. Inductive reasoning was used in the qualitative case study to start from the specific and to move to the general to generate new theory (Rule & John, 2011:98).

3.8.6.3. Reduction of volumes of data

Data reduction of large volumes of data was done by creating themes to ensure the effectiveness of the investigation of the different concepts within the perspectives of

the caregivers (Burns & Grove, 2011:93). The process to transform the raw data into a meaningful picture of the perspectives of the caregivers about the BILS skills training to parents of preterm infants before discharge, included immersion, data reduction, data analyses and interpretation (Burns & Grove, 2011:93).

Data collection was stopped once saturation was reached. Data saturation is when all answers of the research questions were obtained, and no new information is obtained during interviews, resulting in the data collection process being stopped (Rule & John, 2011:109).

All data was stored in an organised manner and ensured easy retrieval at a later stage. The computer that was used by the researcher was protected by a password. Only the researcher and her supervisor had access to the information. As the study progressed the researcher organised the information according to the major themes and ensured that it is available for an external observer/academic to determine the dependability and confirmability to assess the trustworthiness of the study (Houghton, Casey, Shaw & Murphy, and 2013:14).

3.9. Trustworthiness

The researcher adhered to values such as scholarly rigour, transparency and professional ethics during qualitative research, to achieve confidence and trustworthiness within the research community (Rule & John, 2011:107). Rule & John (2011:107) cited Guba (1981), who refers to trustworthiness when credibility, confirmability, dependability and transferability are noted.

The reasoning process of qualitative research required perceptually adding pieces together to create wholes that would give meaning (Burns & Grove, 2011:74). However, identified meanings might be incorrect if the researcher failed to accurately reflect the perspectives of the participants (Burns & Grove, 2011:74). The researcher accepted that there are virtuous and bad interpretations of data with qualitative research. The researcher adhered to scientific rigour, to ensure that data is credible to validate a true reflection of the findings of the study (Burns & Grove, 2011:75).

The researcher ensured that the audit trail ensures that key findings, and the proposal, can be tracked back to the data and data sources. The researcher kept an electronic well-organised file and separate notes of the researcher, which outlined the trail to

demonstrate how claims were made in the study, based on the evidence (Rule & John, 2011:107).

3.9.1. Credibility

According to Burns, et al. (2015; 75) and Rule & John (2011:107), credibility refers to the extent to which the researcher documented or recorded the completeness and essence of the case study, to reflect the views of the participants to enhance the confidence of the reader.

Rule & John (2011:113) argue that a researcher's positionality could influence the credibility and confirmability of the case study. The researcher is also an employee at the Public Secondary Hospital. She used to work in the NNU as a registered midwife. She is currently working at the hospital as a Clinical Programme Coordinator: Nursing Education. The researcher is known to all the health care professional (participants) and has built a professional relationship with them over the years.

Informed written consent was taken days before the individual in-depth interviews and focus group discussions were conducted. One midwife and one doctor were individually interviewed on the same day that they gave consent due to it being the most suitable time for them.

The researcher adhered to the ethical principles by informing all participants when she took consent that they had the right to refuse, that the risk of harm was very minimal and that they had the right to withdraw from the study without any consequences. They were also given an opportunity to ask questions. They were further informed that their privacy and confidentiality would be protected.

The researcher interacted in a professional manner with the participants and

3.9.2. Confirmability

Confirmability refers to the objectivity that the researcher applied without being biased. The full disclosure of the research process, including limitations, the researcher's interest and ethical considerations ensured the dependability and confirmability of case study (Rule & John, 2011:107).

Critical peer checks were performed by the researcher's study supervisor to monitor the interpretation of data and conclusions made to enhance credibility and confirmability of the study (Rule & John, 2011:108). The researcher maintained a chain of evidence. All evidence such as the researcher's field notes in a reflective diary, audio-recordings, electronic data bases were collated in an organised manner (Yin, 2014:127).

All evidence was captured electronically on a computer with a password. Only the researcher and her supervisor had access to the evidence. The evidence will be available for perusal of other external observers such as academics or colleagues, at a later stage to ensure the credibility and confirmability of the entire case study.

3.9.3. Dependability

According to Rule and John (2011:107), dependability in qualitative research is when methodological rigour and coherence are obtained in the findings of cases studies that enhance the acceptance and confidence of the research community. Although a variety of investigations give different results, it does not imply that one is more trustworthy than the other.

The researcher adhered to the proposed methodology and reported the whole process in detail. The same relevant interview guides were used for all the categories of participants, such as the parents who received the BILS training and the midwives and doctors who were involved in the BILS training.

3.9.4. Transferability

According to Houghton et al. (2013:16), in qualitative research transferability is achieved when the results of the study can be applied to a wider population.

Therefore, the researcher had a responsibility to ensure that adequate information about the fieldwork site is available for the reader to make such a transfer. The researcher provided an in-depth description of the case study to ensure that the readers have a good understanding, to enable them to compare the occurrences of the case study report with those seen in their situations (Houghton et al., 2013:16).

The researcher included the boundaries of the study in the research report such as; a single organisation and geographical information; the inclusion and exclusion criteria;

the specific number of participants who participated in the study; data collection methods; the number and length of the interview sessions and lastly the period over which the data was collected (Houghton et al., 2013:16).

3.10. Ethical considerations

3.10.1. Permission from internal review boards

The proposal of the single case study was reviewed by the Health Ethics and Research Committee at Stellenbosch University. The researcher obtained ethical approval from the Health Ethics and Research Committee at Stellenbosch University (09 May 2018, Project ID: 6317, Ethics Reference: #S18/02/030) according to the university's policy.

Permission to perform the study at the Public Secondary Hospital was obtained from the Western Cape Department of Health research sub-directorate, on the 5th July 2018, (Reference: WC_201805_034). Furthermore, approval was obtained from the CEO, Head of Nursing and the Clinical Head of the Neonatal Department at the Secondary hospital.

3.10.2. Consent and Autonomy

As advocated by the Declaration of Helsinki, voluntary written consent was taken from the caregivers of the preterm infants (subjects), to participate in the study to provide their perspectives about the BILS training programme (DoH, 2008:3). The participants rights to self-determination were respected (DoH, 2008:3). They had the autonomy to decide whether they want to participate, or not, in the study (DoH, 2008:3).

Individual consent was taken by providing an information leaflet to the participants and explaining the information on the information and consent forms to the participants. All participants were fully orientated and competent to provide individual consent. None were vulnerable participants who were unable to provide individual written consent. They were given an opportunity to ask questions about the study (DoH, 2008:3).

The participants had the autonomy to voluntary decide to participate in the study (DoH, 2008:3). They were informed that they have a right to refuse to participate in the study. They were informed about the advantages and disadvantages of the study, that they

could withdraw from the study at any time without any consequences (Grove et al., 2015:101).

Consent forms and participant information leaflets were available in English, Afrikaans and isiXhosa. An isiXhosa researcher was available when a participant wanted to be interviewed in isiXhosa. However, all participants preferred to be interviewed in English (Emanuel, Wendler, Killen & Grady, and 2004:931).

3.10.3. Beneficence

The researcher applied the principle of beneficence to do “good” and not to cause harm. Participants were informed that there is a risk that they might become emotionally distressed, however arrangements were made with a social worker to attend to the participant when needed. No participants became emotionally distressed; therefore, no participants were referred for counselling to the social workers at the Secondary Public Hospital. Participants were also informed not to feel obliged to participate in the study, as the HCPs knew the researcher who is also employed at the Public secondary Hospital They were informed that they could withdraw from the study at any time, without any explanation.

The researcher interviewed the parents who attended the high-risk neurological development clinic while they were waiting to be seen by the doctor at the to prevent discomfort by staying longer at the hospital after the consultation. Refreshments were served to the parents after the interviews were conducted as they might not have had breakfast before they left home the morning.

3.10.4. Justice

Furthermore, the researcher applied the principle of justice by treating all participants fairly in terms of benefits and risks of the research (Grove et al., 2015: 98). The parents who received the BILS training were informed that they might not benefit from the research, however it might assist the health care professionals to improve the BILS training programme to empower other parents to save their infants’ life.

All participants were also informed that they will not receive payment to participate in the study. However, refreshments were served to all participants after the individual

interviews and focus group sessions as they might not have had time to eat before the interview took place.

3.10.5. Confidentiality and privacy

All personal and private information about the participants was kept confidential, as the researcher did not share any private information about the participants without their permission. Caregivers were identified as, for example, (Female participant Five and Midwife: 1), (Female Participant Nine and Midwife 2) and (Male Participant and Doctor 1), et cetera (DoH, 2008:3; Grove et al., 2015: -107).

3.10.6. Social value

Emanuel et al., (2004:932), contend that it is essential that ethical clinical research adds social value to the participants and community. Knowledge obtained should ensure enhancements in health. Research without social value exposes participants to risks and misuse of resources.

This study will add social value as the evidence obtained will enhance the BILS training programme at the public secondary hospital. Empowering the preterm parents with BILS training before discharge will empower parents to save their infants' lives. The parents were informed that they might not directly benefit from the study as they have received the BILS training already; however, the research will assist HCPs to enhance the BILS training programme to empower other parents to save their infants lives (Emanuel et al., 2004:931). Parents who are empowered with BILS skills and managed to save their infants live, thereby will add to social value by decreasing the infant mortality rate in the communities of the Western Cape and ultimately the greater society.

3.10.7. Collaborative Partnership

The researcher respected the WCDOH research committee mutual courtesy guide and established a good relationship with the employees and participants at the secondary hospital where the study was conducted. Clear written and verbal communication were ensured in advance when arrangements were made with the Clinical Head and Nursing managers to have access to the participants (Emanuel et al., 2004:932).

The researcher respected the physical space of the hospital and did not interfere with daily routines and operations of the high-risk clinic and the neonatal unit. Furthermore, the researcher displayed her student identity card when she was on the hospital premises (Emanuel et al., 2004:932).

She introduced herself and communicated in a respectful manner to all HCPs and participants of the study. She established a mutual trust relationship with all participants and HCP through honesty and transparency about the logistics of the data collection of the research project at the hospital (Emanuel et al., 2004:932).

3.10.8. Scientific Validity

According to Emanuel et al., (2004:933), “ethics and valid science is an ethical requirement.” Evidence obtained from research must be “reliable and valid data” that could be interpreted and used by the participants/beneficiaries of the research. Research without scientific validity does not add social value.

The researcher took into consideration that recommendations made by parents and HCPs in this study to enhance the BILS training, are feasible and sustainable (Emanuel et al., 2004:933).

3.11. Summary

Chapter one included the background, rationale, problem statement, research objectives and the research methodology described synoptically was an introduction to the foundation of the study. Chapter two revealed a comprehensive literature review on the BILS training evidence and risk factors of preterm infants derived from the various databases. Evidence on perspectives of caregivers involved in BILS training was found.

Chapter three described the research methodology such as the research design, sampling method, recruitment, ethical approval, pilot interview and data collection extensively. In Chapter four the findings of the perspectives of the caregivers involved in the BILS training will be described.

3.12. Conclusion

The aim of the study was to explore and describe the perspectives of the caregivers of preterm infants regarding the BLS skills training before discharge. The research methodology and research design proposed was a descriptive single qualitative case study with two units of analysis. The rationale, background and literature reviewed were discussed.

The data collection, data collection process, data analyses and the trustworthiness of the qualitative research design were discussed. Lastly ethical considerations, the budget and outline for the envisaged study were discussed. In Chapter 4 the findings of the case study will be discussed.

3.13. Operational definitions

Preterm is known as a gestation < 37 weeks' (Barsman et al., 2015:209). An Infant refers to a preterm infant, who has been discharged home from the secondary hospital and are following up at the high-risk clinic at 18 - 20 weeks' corrective age (Maconochie, Bingham, & Skillet, 2015)

Caregivers in this study refer to biological parents, guardians, grandparents, adoptive parents who received BLS skills training. Health care professionals are doctors working in the neonatal unit with preterm infants and midwives providing the BLS skills training to caregivers at the secondary hospital with consent of the biological or legally adoptive parents (Jamieson & Lake, 2013:7).

Cardiopulmonary Resuscitation in this study refers to initiating emergency basic life support to an infant who had a cardiorespiratory arrest. Artificial breathing and cardiac massage are provided to save the infant's life (Oxford, 2008:78).

Basic life support in this study is providing emergency ventilation/breathing and manual cardiac massage to maintain circulation when a preterm infant has a cardiorespiratory arrest (Oxford, 2008:50).

Discharge preparedness Lopez, Anderson and Feutchinger (2012:207), and Jefferies (2014), refer to discharge preparedness as preterm infants being physiologically stable. Therefore, preterm infants must have respiratory stability, be able to maintain their body temperature and feed well. Caregivers must be confident,

attained knowledge and skills to give care to their infants and BILS as prepared by an effective discharge plan (Smith, Hwang, Dukhovng, Young & Pursley, 2013: 415).

A Midwife is a registered nurse who is also qualified and found competent to practice independently as stipulated by the Nursing Act, 2005 (Act 33 of 2005) (s 30(2) (McQuoid-Mason & Dada, 2012). Health promotion and education to caregivers or all patients are key performance areas of Midwives as regulated by the Nursing Act, 2005 (Act 33 of 2005).

4. CHAPTER FOUR FINDINGS

4.1. Introduction

The methodology was discussed in chapter three on how the study was carried out and the trustworthiness of the data was also discussed. Following the data collection, the findings of the caregivers of preterm infants' perspectives on the BILS training before discharge is revealed in this chapter. The aim of the study was to explore the perspectives of the caregivers on the pre-discharge BILS skills training for parents of preterm infants at Mowbray Maternity Hospital, a public secondary hospital in the Cape Town Metropole, in the Western Cape, South Africa.

Findings for this descriptive single case study were analysed in two embedded units of analysis. The first embedded unit of analysis consisted of the parents of preterm infants who received the BILS training before discharge, while the second consisted of the healthcare professionals, who were involved in the BILS training.

4.2. Demographic data

A narrative presentation of the biographical information of a total of seventeen participants is discussed. The biographical data was obtained during semi-structured individual in-depth interviews with four parents of preterm infants who received the BILS training before discharge. Further, the interviews were conducted with four doctors who were involved in the BILS training. One pilot interview with a midwife who provided BILS training to the parents was included. Therefore, a total of nine in-depth interviews were conducted.

Two focus group discussions were carried out, with four midwives per group, who were involved in the BILS training. The first group was composed of managers and the second group comprised midwives who provided the BILS training. There were fifteen (15) females and one (1) male who participated in the study. There were four doctors who were involved in the BILS training and pre-discharge planning with a range of 11 to 18 years' work experience since qualification and about 11 to 18 years' work experience working with infants. The midwives had approximately seven (7) to 32 years' work experience in practice working with infants.

The parents of preterm infants were as follows: participant one was a black female, married, employed and a mother of one. Participant two was a black female, single mother of four children, unemployed and receives a social grant for her four children. The father of the children does not live with them.

Participant three was a black female, married mother of two children, unemployed, and her husband works as a general assistant. Lastly, participant four was a coloured female, married mother of three children, unemployed and her husband is self-employed.

The pilot individual in-depth interview with a midwife which was included in the study included the following: participant five is a coloured female midwife, married and a mother of two. She has seven years' work experience in perinatal care, including three years of work experience in neonatal nursing. She is working in the high-care area of the NNU and has been providing BILS training to the parents in the KMC ward in the absence of the midwife assigned to the KMC ward.

The midwives who participated in the first focus group included the following: participant six is a coloured female midwife who has twenty-four years perinatal healthcare work experience, mostly in neonatal nursing. She provided BILS training to the parents in the (KMC) ward and as the clinical facilitator provided BILS training to midwives. She is currently the operational manager of the postnatal ward.

Participant seven is a coloured midwife who has 25 years of work experience in perinatal care at the public secondary hospital. She has been the operational manager in the (NNU) for the past seven years. BILS education is part of her portfolio of training.

Participant eight is a coloured female who is fairly new at the hospital. However, she has 18 years of work experience in perinatal care, including work experience in neonatal nursing for the last 10 years. She is a senior midwife and involved in BILS training.

The ninth participant was also part of the first focus group discussion. She is a white female midwife employed at the public secondary hospital for 10 months. She has 23 years of work experience in neonatal nursing and previously managed the (KMC) ward at another hospital where she was also involved in the BILS training. Currently her

involvement in the BILS training involves supporting the operational manager of the (NNU) from a managerial perspective.

The second focus group was composed of the midwives involved with the training as indicated in chapter three. Participant ten is a white 49-year-old female midwife, married with two children. She has been employed at the public secondary hospital for 11 years, with 30 years of neonatal and paediatric work experience and currently working in Neonatal Intensive Care Unit (NICU). She currently provides BILS training on weekends or in the absence of the midwife who is assigned to the kangaroo mother care ward (KMC) ward.

Participant eleven is a female midwife, unmarried, 33 years old, who does not have children. She has been employed at the secondary public hospital for 10 years with perinatal care work experience. She is currently a clinical facilitator at the hospital and provided BILS to parents before and providing BILS training to midwives.

Participant twelve was involved in focus group two and is a coloured female midwife, a widow with two children. She has been employed at the public secondary hospital for 32 years, thus has 32 years of work experience in perinatal care and specialises in neonatology. She is providing BILS training to the parents in the absence of the midwife who is assigned to (KMC) ward.

Participant thirteen is a white female midwife who has two children and has been employed at the public secondary hospital for 14 years. She has been working at the hospital for 14 years in the (KMC) ward and is assigned to the KMC ward where she mostly provides the BILS training to parents before discharge.

The four individual interviews with the doctors included: participant fourteen was involved in the individual interview and is a 58-year-old male working at the public secondary hospital for 18 years as a paediatric consultant. His involvement in the BILS training is advisory and supportive. He identifies and prescribes BILS training for parents of preterm and high-risk infants.

Participant fifteen is a white female doctor who has been working at the public secondary hospital for 12 years. She encourages parents in the KMC ward to

overcome their fears and anxiety to provide BILS training. She prescribes BILS training for caregivers of preterm and high-risk infants.

Participant sixteen is a white female doctor who is married and has two children. She has been permanently employed at the public secondary hospital for 11 years. She was involved in the individual interview as she was doing outreach and managing the high-risk follow-up clinics in five communities. Four of these high-risk clinics at the midwife obstetric units refer the high-risk mothers and infants to the public secondary hospital. She receives feedback from parents who received the BILS training, who are following up at the high-risk baby clinic.

Participant seventeen was involved in the individual interview and is a coloured female who is married, has two children and has been employed at the public secondary hospital for twelve years. Her speciality is micro preterm infants, extreme low birth weight less <1000 grams. Her involvement in BILS is reinforcing and evaluating knowledge by quizzing parents in the KMC ward to ensure BILS knowledge is retained. Furthermore, she identifies parents of high-risk infants and prescribe BILS training for them.

4.3. Embedded Unit of Analysis One: parents of preterm infants

Three themes emerged from the data while the principle theme perspectives of parents were deduced from the objectives. The themes that emerged included basic life support training, discharge information and development factors. The table below describes the themes and subthemes.

Table: 4.1: Embedded unit of analysis one themes and subthemes








Themes	Subthemes
Basic infant life support training	<ul style="list-style-type: none">  Feeling empowered  Empowering others
Discharge information	<ul style="list-style-type: none">  Ongoing training  Sharing information
Development factors	<ul style="list-style-type: none">  Educational levels  Language barriers  Information overload

Table Subthemes and categories formulated

Subthemes	Implications expressed
<ul style="list-style-type: none"> ✚ Feeling empowered 	<ul style="list-style-type: none"> ✚ (BILS) knowledge and skills gained (C2) ✚ Method used instruction and demonstration ✚ Learnt about self (C2) ✚ Reflection on (BILS) training (C2) ✚ Changed preconceived negative perceptions (C2) ✚ Caregivers applied (BILS) after discharge (C4) ✚ Managed emergency successfully after discharge (C4)
<ul style="list-style-type: none"> ✚ Feeling empowered 	<ul style="list-style-type: none"> ✚ Caregivers perceived anxiety initially (C2) ✚ Caregivers perceived self-blame (C5) ✚ Caregivers felt competent, confident, empowered and felt proud (C2) ✚ (BILS) application challenging to own infant (C4) ✚ Gained knowledge, felt reassured (C2) ✚ Felt grateful and appreciated (BILS) training received
<ul style="list-style-type: none"> ✚ Empowering others 	<ul style="list-style-type: none"> ✚ Empowered to share (BILS) information with others ✚ Caregivers taught (BILS) to others ✚ Caregivers shared (BILS) perspectives after discharge with each other
<ul style="list-style-type: none"> ✚ Ongoing training 	<ul style="list-style-type: none"> ✚ (BILS) pamphlet ensure futuristic refresher information (C2) ✚ (BILS) on illustrated on pamphlet (C2)
<ul style="list-style-type: none"> ✚ Sharing information 	<ul style="list-style-type: none"> ✚ Shared (BILS) information leaflet with others (C2)
<ul style="list-style-type: none"> ✚ Educational levels 	<ul style="list-style-type: none"> ✚ Understood as first aid (C3) ✚ Keep (BILS) training basic ✚ Information is processed differently (C2)
<ul style="list-style-type: none"> ✚ Language barriers 	<ul style="list-style-type: none"> ✚ Simplified English was used ✚ Caregivers resisted (BILS) training
<ul style="list-style-type: none"> ✚ Visualization of demonstrations 	<ul style="list-style-type: none"> ✚ Use automated mannequins to create real situations
<ul style="list-style-type: none"> ✚ Information overload 	<ul style="list-style-type: none"> ✚ Continue with (BILS) training (C2) ✚ (BILS) training to remain unchanged

4.3.1. Theme one: Basic infant life support training

The theme basic life support training had three subthemes emerging which included empowering self, emotionally empowered and empower others. The implications expressed under each sub theme are discussed below.

4.3.1.1. Subtheme: Feeling empowered

Parents who received the BILS training shared that they have gained BILS knowledge and skills to save their infants' lives. They did not have any information about BILS before training, then felt equipped and confident to provide BILS to their preterm infants after discharge.

Basically, what I was taught is how to save the baby when the baby is suffocating. I found the training informative because I didn't know anything, you know (Female Participant one, Mother).

Reflecting on the BILS training, parents revealed that they learnt about themselves. Parents felt empowered by the BILS training. As parents reflected on the BILS training received they also shared that the training method was instruction and demonstration. According to the parents, visualisation of the BILS demonstration ensured effective learning. The BILS training received before discharge of the preterm infants resulted in the parents negative preconceptions about public healthcare being changed.

Like if you are a first-time mother, you don't know anything, but learning for yourself it's more important, I did the CPR training, and it's not just about babies, because it can save an older person. You get to talk to the nurse and they explain to you and she was using that doll to do a demonstration. So, it was much easier. For me, this whole involvement changed my perspective from what I used to hear about people saying about public hospitals (Female Participant one, and Mother)

Parents provided feedback that their infants stopped breathing after discharge and that they utilised the BILS training to help their infants. Parents initially panicked but initiated BILS, called for help, arranged transport to the nearest healthcare facility and managed to save their infants' lives. Parents are empowered with BILS knowledge and skills to manage life-threatening events after discharge.

I didn't notice the baby is not breathing, then something told me, no, the baby is not breathing. I started to panic. I asked the lady who lives behind my house, so I told her what to do. Yes, I showed her the "pressing", because the baby was not breathing. She did that, and then the baby came back again. So, I ran to the next door to ask the car to hospital C. When we got there at the hospital, all the doctors came. So, the doctors woke up the baby. (Female Participant three and Mother)

Similarly, another parent identified danger signs that her infant became cyanotic "turned blue" and was struggling to breathe. She initiated BILS, arranged transport, the taxi took them to the nearest healthcare facility. She emphasised the importance of staying calm during an emergency.

He was turning blue, and he was like struggling with his breath, yes. I gave him the "punch" compressions, and the mouth to mouth. Then we had to go to the clinic. Yes, then I just got in the taxi. I just asked the driver, can you just give me a lift to the clinic because I have an emergency now, Yes, I breathed for him. What I learnt is that, you as the mommy, you must stay calm, yes, because if you are going to panic, it's going to get worse. (Female Participant four and Mother).

In conclusion, the first participant shared that BILS training method was instruction and demonstration. She felt confident that she is equipped with BILS knowledge and skills as visualisation of the demonstration ensured effective learning. The other two parents were empowered to identify danger signs when their infants stopped breathing and provided BILS after discharge.

The one parents panicked but called for help and empowered her neighbour to provide BILS while she made transport arrangements. In contrast, the other parents emphasised the importance to stay calm during an emergency. This study shows that parents are empowered to provide BILS and to manage life-threatening events after discharge.

Parents revealed that they initially felt anxiety and self-blame; however, they felt calm, competent, confident, empowered after they received the BILS training. The BILS training made them feel reassured. Parents felt grateful that they received the

BILS training.

I felt more at ease, because the stress, especially with being a first-time mum, is how am I going to do this? So, when I got the training, it was helpful. Not just helpful, but it also added knowledge. So, I did feel a little bit at ease that at least there is something that I know what to do in case we have this kind of situation that I can be able to save my son. (Female Participant one and Mother)

A second participant revealed that she felt self-blame as she used a paraffin heater which could have caused the infant to stop breathing due to inhalation of paraffin fumes. She was taught to avoid using paraffin, but she forgot. She felt grateful that she was taught BILS and that she knew what to do when her infant stopped breathing.

I was going to blame myself if my baby died. Because they told me I must not use paraffin heater. I forgot. I want to say thank you for teaching us, because if I didn't get the lessons, maybe the baby would have died, because I would not have known what I was supposed to do. (Female Participant three and Mother)

Both participants felt different emotions. The first participant revealed that she initially felt anxious as a first-time mother. The second participant shared that she had feelings of self-blame as her infant inhaled paraffin fumes which caused the infant to stop breathing. Yet, both participants felt empowered, confident and grateful due to the BILS training they received.

4.3.1.2. Subtheme: Empowering others

Parents who received the BILS training felt prepared and confident to empower others. Parents provided feedback that they taught others BILS, such as: a neighbour during an emergency, their husbands and a nanny. Empowering others with BILS ensures ongoing education.

So, it's something that can be passed on, you can make a difference if they go out there and teach other people. Education should be an on-going thing. So, I would give it to my friends. My husband wasn't with, but I did tell him, I did show him the page, when I got a nanny, I also told her, and I showed her. (Female Participant one and Mother)

A Parent's emotional response during an emergency was that she became anxious when she realised that her preterm infant became apnoeic, "stopped breathing." She called her neighbour and taught her neighbour during the emergency to provide BILS to her infant.

I started to panic. I asked the lady who lives behind my house, she is renting, so I tell her what to do. Yes, I showed her the pressing, because the baby was not breathing. She did that, and then the baby came back again. (Female Participant three and Mother)

This study reaffirms that parents are making a difference by empowering family members and neighbours with BILS information to save their infants lives. The first participant provided BILS training to her nanny and husband. The second participant equipped her neighbour during the emergency with BILS skills successfully. She managed the emergency successfully, even though she felt anxious.

4.3.2. Theme two: Discharge information

Under this theme two subthemes emerged: ongoing education and sharing information. The indications expressed under each sub theme are discussed below.

4.3.2.1. Subtheme: Ongoing education

According to the parents who received the BILS training, pamphlets were provided as discharge information. The BILS steps are illustrated on the pamphlets. The discharge information ensures ongoing education. The pamphlets are also a refresher tool for parents to refresh their BILS knowledge.

They gave us the small papers. There are pictures, picture number one showing you what to do when the baby is not breathing. Yes, for every step there is a picture. (Female Participant three and Mother)

I was given a pamphlet and I can still go back there now to refresh my memory. (Female Participant one and Mother)

Participants revealed that the BILS steps are illustrated with pictures for each step, visualisation makes it easier to reinforce information. Parents are refreshing their BILS knowledge which results in ongoing education.

4.3.2.2. Subtheme: Sharing information

Parents have empowered their family members by sharing the BILS information with them and others. They shared the information with their husbands and one husband also provided the BILS to the preterm infant after discharge.

The information that I got home with me is mostly what I did. I did take the information home. I actually trained my husband also. So, when I'm taking too long, and then he's doing it, the "mouth to mouth" and the "punch". He helped me a lot. (Female Participant Four and Mother)

Parents divulged that they are willing to equip others with the BILS information they received, by sharing the pamphlets with others.

If I want to make copies for other people, I can just take it and make copies for other people and give it to them. (Female Participant one and Mother)

This study established that parents are empowering family members with BILS information and are sharing the BILS discharge information to save their infants lives.

4.3.3. Theme three: Supporting factors

Under this theme three subthemes emerged: educational levels, language barriers and information overload. Parents suggested BILS training remains unchanged as it accommodates all educational levels, overcomes language barriers and prevent information overload. Parents are coming from different backgrounds and educational levels.

4.3.3.1. Subtheme: Educational Levels

Parents suggested that BILS training be kept basic, to accommodate all educational levels. BILS information was processed differently due to different educational levels. One caregiver understood BILS is an equivalent to first aid. She also shared that she did not have basic education.

The nurse taught me first aid. When he forgets to breathe, I know how to make first aid. I never went to school, you see, because my mother, I am coming from the village, Eastern Cape village, you see. (Female Participant two and Mother)

Caregivers' viewpoints were that BILS training remains unchanged as it was good training.

So far, I wouldn't say that there is anything that they should change, it was like basic training. But that training is good training. (Female Participant one and Mother)

Parents agreed that the BILS training should remain unchanged as it accommodates different educational levels. One first participant did not attend school, she understood BILS as first aid. She spoke English fairly well, yet, found it difficult to express herself. However, she says that she knows what to do.

4.3.3.2. Subtheme: Language barriers

Parents revealed that simplified English was used during BILS training sessions. Simple English could ensure that all parents understand the steps of BILS.

So, I love the training because one, the English that they used, it's simple English that we all can understand, and even the steps that they are taking. It's like easy steps. (Female Participant one and Mother)

Caregivers revealed that some parents did not understand English. Other parents interpreted the (BILS) information to them in isiXhosa or their own language. Parents' views are that visualisation of demonstrations reduces language barriers during BILS training.

They don't know English and they don't know we must learn to speak English. They don't like English, and if someone listen in English, they will repeat it to you in Xhosa or in your language. I try to speak for myself English, but I am not perfect.

The first participant's view was that the BILS training was provided in simple English which made it easier for caregivers to understand. Yet, the second participant revealed that some parents did not understand English. However, the BILS information was translated to them by other caregivers after the BILS training.

4.3.3.3. Subtheme: Visualization of demonstrations

Parents' views are that visualisation of demonstrations are more effective as it accommodates language barriers and all educational levels and more effective learning.

I think the training must look like alive, so that the other mummies can take it seriously. Like maybe the doll is talking. (Female Participant three and Mother)

So, it's all the information that you need, but the good thing is that apart from that information, you get to talk to the nurse and they explain to you. She took a doll and she was using that doll as a demonstration on how to do this, how to do this. So, it was much easier. (Female Participant one and Mother)

In conclusion, both participants perspectives were that visualization of demonstrations ensure more effective learning.

4.3.3.4. Subtheme: information overload

Parents who received the BILS training before discharge suggested that the BILS training should continue. BILS training should remain unchanged to prevent confusion and information overload.

I wouldn't want them to change it, or I wouldn't want them to add, because adding might cause more confusion. If you now change something and you give more information, it might become information overload, because we process things differently. (Female Participant one and Mother)

One participant's perception was the BILS training information provided was just too much. To prevent information overload only the basic information of BILS should be provided.

I think the training was just a bit too much. It is like too much info, so they can just stick to the basics. (Female Participant four and Mother)

Both participants felt that information overload should be prevented. The first participant felt that it should remain unchanged to prevent information overload. Yet, the second participant felt that the BILS training information was too much. The contrast in their views illustrates that participant's process information differently. Suggestions were made by both participants to keep BILS training basic.

4.4. Embedded unit of analysis two: Perspectives of HCPs on the BILS training

Three themes emerged from the data when the principle theme perspectives of health care professionals were deduced from the objectives. The themes that emerged included motivation for BILS training before discharge, BILS provided and enhancement of the BILS training. The table below describes the themes and subthemes.

Table 4.2: Principle theme two: perspectives of HSPs

Themes	Subthemes
1. Motivation for BILS training before discharge	<ul style="list-style-type: none"> ✚ Empowerment of preterm caregivers ✚ Preterm infants risk factors after discharge
2. Providing BILS training	<ul style="list-style-type: none"> ✚ perspectives on providing BILS training ✚ Identifying danger signs ✚ Empowering of parents ✚ Effectiveness on BILS ✚ Challenges of providing BILS training
3. Supporting the BILS training programme	<ul style="list-style-type: none"> ✚ Develop a BILS video ✚ Developing individual BILS plans ✚ Implementing support groups BILS ✚ Implementing BILS training at all birthing institutions ✚ Monitoring of BILS training ✚ implementing prevention and promotion strategies in the BILS programme

Table 4.3: Subthemes and meanings formulated HCPs

Subthemes	Categories
Empowering caregivers	<ul style="list-style-type: none"> ✚ Empowering all preterm infant parents ✚ Empowering community healthcare workers
Preterm infants risk factors after discharge	<ul style="list-style-type: none"> ✚ Preterm infants prone to apnoea ✚ Preterm infants clinically well but systems immature ✚ Prone to post discharge infections ✚ Prolong hospitalization, death after discharge ✚ Sudden infant death syndrome ✚ Socioeconomic circumstances at home
Perspectives on providing BILS training	<ul style="list-style-type: none"> ✚ Method (BILS) training Instruction and demonstration ✚ Empower caregivers and family with (BILS) ✚ Recordkeeping of (BILS) training ✚ Importance of (BILS) discharge information ✚ Mentoring of midwives during (BIL) training ✚ Evaluation of (BILS) knowledge before or after training ✚ cost-effectiveness/feasibility of (BILS) training
Identifying danger signs	<ul style="list-style-type: none"> ✚ Identifying what is normal and abnormal
Empowering parents	<ul style="list-style-type: none"> ✚ Support to caregivers, fear, anxiety, low confidence (Dr2, Dr4)
Effectiveness of BILS training	<ul style="list-style-type: none"> ✚ Positive feedback on (BILS) training from caregivers ✚ Negative feedback on (BILS) training ✚ Doctor's personal (BILS) perception
Challenges providing (BILS) training	<ul style="list-style-type: none"> ✚ Shortage of human resources ✚ Challenges with time constraints for BILS training ✚ Lack of equipment ✚ Challenges with transport after discharge
Developing individual video	<ul style="list-style-type: none"> ✚ Visualization ensures effective mass learning ✚ Video ensures ongoing (BILS) training ✚ Visualization accommodate language barriers
Keep (BILS) training basic	<ul style="list-style-type: none"> ✚ Basic information empowers everyone ✚ Consider literacy and educational levels
Developing individual plans	<ul style="list-style-type: none"> ✚ Caregivers compile their own individual (BILS) plans

Implementing BILS support groups	<ul style="list-style-type: none"> ✚ (BILS) support group and communication platform ✚ Caregivers share their perspectives after discharge ✚ Experts providing evidence based (BILS) advise
Implementing (BILS) training all birthing institutions	<ul style="list-style-type: none"> ✚ Empowerment all caregivers of infants ✚ Systemising the BILS training programme ✚ Empowering all HCW's
Monitoring of (BILS) training	<ul style="list-style-type: none"> ✚ Healthcare facilities to capture and provide data
Implementing prevention and promotion strategies in (BILS) programme	<ul style="list-style-type: none"> ✚ Advantages of breast feeding ✚ Advantages of kangaroo mother care ✚ Infection prevention and control strategies ✚ Therapeutic identify danger signs

4.4.1. Theme one: Motivation for BILS training before discharge

Under this theme two subthemes emerged, empowering of preterm caregivers and preterm infants' risk factors after discharge, and these emerged inductively during content analysis from the coding and categorisation. This theme discusses the importance of equipping parents with BILS knowledge and skills. The in-depth justification for BILS for preterm infants' parents is discussed below.

4.4.1.1. Subtheme: empowering of preterm infant parents

Healthcare professionals' perspectives are that BILS training before discharge is needed to empower parents of preterm infants with BILS training before discharge. Parents should be empowered with BILS knowledge and skills to manage life-threatening events after discharge.

These infants are at risk of having life-threatening events after discharge which could cause death after discharge. Another option would be to empower community healthcare professionals to support parents to identify danger signs and to provide BILS after discharge.

Well, it's to do with empowerment of the mothers. The rationale, it comes out of regularly getting reports of ex-prems going home, and then having either acute life-threatening events or dying at home. So, your options are then community health workers or these parents themselves. So, if one is to train mothers and educate mothers about danger signs and what to do in an

*emergency, then you can empower the people who are closest to the baby.
(Male Participant Fourteen and Doctor)*

Preterm infants are prone to apnoea after discharge. Therefore, parents should be equipped to identify danger signs and to save their infant's life. It will also prevent parents blaming themselves if a preterm infant dies after discharge.

*So, I don't want to put my parents through that, a baby dying and them thinking it's their fault. But something like basic life support is vital for these parents, so that if they find their baby soon enough after a baby possibly has had an apnoea episode, so they can start basic life support and save this child's life. It's vital.
(Female Participant fifteen and Doctor)*

The importance to provide BILS to parents is emphasised due to the first year of a preterm infant being critical. Therefore, it is important for preterm parents to receive BILS training before discharge.

Having a prem, it's a very high-risk baby. But that first year of their life is very critical. From my own perception now, it's imperative that mummies know how to resus their babies. (Female Participant Seventeen and Doctor)

All HCPs agreed that preterm infants are still at risk of life-threatening events such as apnoea after discharge. Therefore, preterm infant parents need to be equipped with BILS training before discharge to save their infant's life. Another option is to equip community health care workers to assist parents with identifying danger signs and BILS in the communities. However, the parents are still the closest people to the preterm infant.

4.4.1.2. Subtheme: Preterm infants risk factors of preterm infants after discharge

This subtheme discusses risks that preterm infants are clinically well when they are discharged; however, these infants' systems are still immature. Therefore, preterm infants are still prone to apnoea, sudden infant deaths and infections post discharge due to their immature immune systems. They are also discharged to socioeconomic circumstances where they are exposed to inhalation of smoke, unhygienic circumstances and substance abuse.

Premature babies are prone to having apnoea of prematurity.

Well, sometimes they've got an infection, for example respiratory syncytial virus, RSV. Sometimes it can be a bacterial infection. (Male Participant Fourteen and Doctor)

If there is anything, like any respiratory virus or anything compromising to the threshold, so they are much more at risk of having an apnoea attack? (Female Participant Fifteen and Doctor).

Health care professional HCPs' viewpoints are that preterm infants had long periods of hospitalisation and sadly death sometimes occurs soon after discharge.

There is the ongoing child death review, based here in Cape Town and in Phoenix in Durban, where ex-prems are presented under babies who are dying. In May in 2014, it was said that out of the 60 odd child deaths, eight of them had been ex-prems. So, very much over-represented. Last week, it happened that way, a mom went home, and her baby died at home. (Male Participant Fourteen and Doctor)

They, furthermore, revealed that preterm infants are at greater risk of sudden infant death syndrome (SIDS) after discharge. For example, the infant was well but suddenly died during the night without any explanation.

It's all going well, and you have got a good mom, it is so sad to hear, a week later after she went home, the baby died at home. But it really is a sudden infant death syndrome, which is much more common in the premature babies. There is no infection found, baby didn't have gastro, a cold, pneumonia, he had no infection, he had no obvious reason, but he suddenly died in the night without any explanation. (Female Participant Fifteen and Doctor)

Preterm infants are discharged to socioeconomic circumstances at home where they are at risk of environmental hazards. Some of these environmental hazards cause infections which can result in apnoea.

So, they live in a house with lots of people staying there, so it's over-populated, everybody smokes, people use drugs. There's no food security, there's no housing security, and children get cold. It's very sad. Flu and colds, those kinds

of viruses are deadly to premature babies. (Female Participant Seventeen and Doctor)

In conclusion, HCPs views are that preterm infants are discharged in a clinically stable condition; however, they are still prone to apnoea and infections due to their immature systems. Furthermore, they are at greater risk for SIDS and exposed to socioeconomic circumstances where they are exposed to smoke inhalation, poor food and housing security which could result in death soon after discharge.

4.4.2. Theme two: Providing BILS training

Under this theme five subthemes emerged: Perspectives on providing BILS training, Identifying danger signs, g, empowering parents, Effectiveness of BILS training and challenges of providing BILS training. The implications expressed on BILS training provided are discussed below.

4.4.2.1. Subtheme: Perspectives on providing BILS training

HCPs were reflecting on the BILS training and shared that group sessions of BILS training is provided twice a week. Smaller groups are preferred to ensure effective learning and to give attention to all parents.

Well, I try to do resus training twice a week. (Female Participant Thirteen and Midwife)

I find that a smaller group is better than a massive group, you know, than 24. You always lose somebody. If it's a small group, you make them feel special (Female Participant Ten and Midwife)

BILS is provided twice a week. HCPs reason that smaller groups ensure more effective learning as attention could be provided to all caregivers.

The method used for BILS training is instruction and demonstration in a light-hearted manner; however, BILS is a serious matter and trainers need to ensure that the parents retain the information.

I try and make it fun, because it is a serious matter, if you create a fun environment, they're going to remember it quicker and easier. And obviously

also do a demonstration using a mannequin (Female Participant Eleven and Midwife)

HSPs elaborated on the importance to empower the parents and other family members of the preterm infant to reinforce her support system.

There will be some cases where the mom will not know what to do, or she will forget, or she will be too anxious to do it. So, I ask them if the dad is also there, to teach the others at home also to do it, to reinforce her support system. (Female Participant Six and Midwife)

Perceptions of HCPs were also that BILS should be provided to the fathers and the extended family.

I think all babies. I think they should just do it both often to both mom and dads, and then maybe the extended family that comes to visit often as well. (Female Participant Five and Midwife)

Both participants' viewpoints are that the fathers of preterm infants and the extended family be included when BILS training is provided to parents. The first participant identified that empowering the family will reinforce the parent's support system at home after discharge.

HCPs elaborated on the steps of BILS and revealed that it is explained to preterm parents in a simplified manner. According to HCPs, breathing is the most important step due to preterm infants having mostly cardiorespiratory arrests.

Firstly, shout for help, start to breathe for the baby, put your mouth over the baby's mouth or nose, and blow some air, which is the main thing, because most of the premature and most of the baby cardiac arrests would be respiratory cause. (Female Participant Fifteen and Doctor)

Parents are instructed to stay calm, and while someone is calling the ambulance, provide BILS to keep the infant alive.

So, but I think to emphasise and keep teaching them and telling them not to stress, while the next person is helping them, calling the ambulance, just to help keep their baby alive. (Female Participant Five and Midwife)

The BILS training sessions are more of a discussion to involve the parents and to ensure participative learning.

It's more of a discussion, more than just me standing there and lecturing. So, you get them quite involved, you engage them, you ask questions as you go along, etc. (Female Participant Eleven and Midwife)

Furthermore, according to HCPs, mentoring of midwives and student midwives could be done during BILS training sessions with caregivers to equip them to teach others.

I do the training with all of them rather, with some staff member with me, so that she in turn can relay it again to somebody new. That is basically it. I would maybe involve a student nurse or somebody who wants to see how it's done, I take my time. (Female Participant Six and Midwife)

An induction programme for the newly appointed midwives who are community service practitioners, has been implemented at the hospital. Various topics, including BILS training to parents, have been covered on the induction programme.

So, we have an induction program for all the newly appointed community service nurses on various topics. So, the basic life support, and the demonstration to moms for preterm infants, prior to discharge. (Female Participant Eleven and Midwife)

Healthcare professionals evaluate parents' BILS knowledge before or after BILS training sessions to reinforce information or to build on information.

We sometimes quiz the mummies in KMC about what they learnt. If we are very worried about a certain baby, we quiz this mom a few times, to make sure that she does know what is happening. (Female Participant Seventeen and Doctor)

I say okay, maybe Mommy K can you perhaps tell us what we should do? Then that tells you okay, was she listening or wasn't she listening, and then just build on that. I tend to ask questions afterwards (Female Participant Ten and Midwife)

Both participants evaluated the parents' BILS information to build on information and to get an indication if they were listening. Participants revealed that they would quiz

the parent who has a preterm infant, who is at greater risk for life-threatening events after discharge, to ensure that the BILS knowledge is reinforced.

Healthcare professionals' perspectives are that recordkeeping of BILS training provided to parents is important. Monitoring and evaluation of BILS could be done through documentation as proof that the BILS was provided.

We make sure, a resuscitation booklet that we have is filled in, but we also write it in their folder as well, and then we make sure that is part of the discharge tick list that the moms have had resuscitation training, that they know what to do. (Female Participant Seven and Midwife)

BILS is recorded in the preterm infants' files to ensure proof that it was done.

I try and look through the files quietly before I start. (Female Participant Ten and Midwife)

Both participants revealed the importance that recordkeeping of the BILS training is done for monitoring and evaluation purposes of the BILS training.

Healthcare professionals also emphasised the importance that BILS discharge information be provided to parents after the BILS training was provided to ensure a BILS guideline after discharge.

We give them a little pamphlet as well, so that if they go blank, we always tell them put it on your fridge, it's a guide for you. (Female Participant Five and Midwife)

BILS information pamphlets are provided to parents after BILS training, to have a guideline to refresh their BILS information after discharge.

A justification to optimise the expensive healthcare preterm infants received before they were discharge is to provide BILS training to parents before discharge.

To me it seems to be a huge waste of resources if we keep a baby in here for two to three months with ventilation and TPN and all kinds of things, and then we send them home, only for them to die a few days after going home. (Male Participant Fourteen and Doctor)

Healthcare professionals' perspectives are that the BILS training provided before discharge is cost effective and feasible.

So, we need to do what's feasible, and what's feasible is having a mom that can know what to look for, early warning signs and react to and do a basic resuscitation if her baby deteriorates. It doesn't cost anything, and that can save a life. So, I think that's why it's feasible. (Female Participant Sixteen and Doctor)

Most participants reflected on how the BILS training is provided and described that group discussions are provided to ensure participative learning. Family members of parents are included to ensure their support system. The BILS Steps are explained in a simplified manner and mentoring by midwifery students and midwives are done during BILS training.

The importance of discharge information and recordkeeping of BILS for monitoring and evaluation is discussed. Lastly BILS is cost effective and feasible, therefore BILS training before discharge is advocated to optimise the expensive healthcare preterm infants received before discharge, and to save the lives of preterm infants after discharge.

4.4.2.2. Subtheme: identifying danger signs

Parents are taught to identify danger signs to be able to identify what is normal and what is abnormal to provide BILS to their preterm infants when it is required.

So, before I go into the resuscitation part of it, I tell them what the abnormalities are, what the normal thing is. So, if they can recognise a normal, well baby, they will be able to recognise if the baby is not doing well. (Female Participant Eleven and Midwife)

Views of HCPs are that when parents are equipped to identify early warning signs, they could get medical help before the infant has apnoea.

If she can pick up on those signs, early warning signs of her baby not being well, things like not feeding, colour slightly off, or maybe a little bit lethargic. (Female Participant Sixteen and Doctor)

In addition, the HCPs standpoint is that parents, who have been taught to identify danger signs, will be able to manage an emergency after discharge.

So, if one is to educate mothers about danger signs and what to do in an emergency, then you can empower the people who are closest to the baby, that they will have something to do in an emergency. (Male Participant Fourteen Doctor)

This study emphasises the importance of equipping preterm caregivers to identify danger signs. Parents who are empowered to identify danger signs could seek medical help early before the infant stops breathing or identify signs that the infant stopped breathing and manage an emergency successfully after discharge.

4.4.2.3. Subtheme: Empowering of parents

Perceptions of HCPs are that caregivers are feeling reassured and competent after BILS training.

Having a mother trained and initiating life support immediately, it may have some benefit. But I think it does give the mothers some comfort, you know, that they feel competent. (Male Participant Fourteen and Doctor)

One HCP revealed that she performed BILS on her own preterm infant and that it was the most stressful situation she had been through.

It was one of the most stressful situations that I had been through. I had to perform CPR on my child, to the Hospital, that was the longest ride of my life. (Female Participant Seventeen and Doctor)

Parents are encouraged and supported to stay calm during an emergency, and some caregivers are more confident than others.

We tell them to stay calm. But it's scary for most moms. So, we try and emphasise, we try and encourage, we try and support. Then you get those confident moms that say, I will be able to do that for my baby. (Female Participant Five and Midwife)

Another (HCP) shared that she noticed in the past that parents gained self-confidence after BILS training was provided.

I think from my past-work experience, what I saw is if you teach the mom, you empower them, they get a lot of self-confidence. (Female Participant Eight and Midwife)

This study discusses the views of HCPs on empowering parents of preterm infants during BILS training. They are supporting caregivers to prevent, or manage, fear, anxiety and low confidence levels. Empowering caregivers with BILS training build's their confidence levels and reassures caregivers.

4.4.2.4. Subtheme: Effectiveness of BILS training

Healthcare professionals provided positive and negative feedback on effectiveness of the BILS training received, from colleagues and parents after discharge of a preterm infant.

Many of them survive and they do very well, especially if their parents know how to do basic life support. It's worth it. It's worth it (Female Participant Fourteen Doctor)

I've had a few episodes where a mother has started initial CPR in the sense of giving the baby breaths and starting compressions. That has made a massive difference in that baby arriving at the hospital and there was no loss of circulation. And just off the top of my head, at least three or four times. (Female Participant sixteen and Doctor)

Healthcare professionals are receiving feedback that parents who have been in the KMC ward, have formed WhatsApp groups to provide feedback to each other. Feedback included if the infant was hospitalised after discharge and how they provided help to their infant.

In the KMC area, what some of the moms will do, because the infants are in the nursery for so long, the moms form a bond with each other they started a WhatsApp group amongst them, giving feedback on if the baby did land up at Hospital A, what they did to help the baby. That is how we get our feedback. (Female Participant Seven and Midwife)

Healthcare professionals received anecdotal reports from clinicians at other hospitals that they admitted a preterm infant whose caregiver initiated BILS at the hospital and saved her infant's life.

I have had anecdotal feedback from other hospitals, like at hospital A. There was one baby who had apnoea's there and stopped breathing, and the mother initiated what she had learnt at Hospital M, and then the baby did well, and we got positive feedback from the clinicians at Hospital A to say they were very impressed that the mother knew how to do basic life support. (Male Participant Fourteen and Doctor)

These participants established that healthcare professionals are receiving positive feedback that parents provided BILS successfully at a high-risk clinic, follow-up visits in the communities, via word of mouth from other parents and from parents who are in contact via social media. Furthermore, anecdotal reports from clinicians at Hospital A, were received that a parent whose preterm infant became apnoeic at the hospital, initiated BILS successfully.

Healthcare professionals also, however, provided negative feedback that preterm infants died after discharge at another healthcare facility. They would then determine if the parent received BILS training.

Now and then a doctor will say this one died at Hospital C, then they will draw the folder and check if it's had resus training. That's the kind of feedback I get. (Female Participant Nine Midwife)

According to HCPs, parents are in contact with each other. Word of mouth feedback was provided by parents that a friend who has been discharged, contacted them and informed them that their preterm infant died soon after discharge.

Well, no negative feedback on the life support training itself, but I suppose the only negative feedback is those cases where basic life support was unsuccessful. Now, it's word of mouth you will find that a mom who is still in KMC hears from her friend who was discharged the week before. Last week it happened that way, a mom went home, and her baby died at home. (Male Participant Fourteen and Doctor)

In conclusion, both participants revealed that preterm infants are dying after discharge. No negative feedback on the BILS training was revealed, as the view of the second participant is that the only negative feedback is when the BILS provided to the infant was unsuccessful.

A healthcare professional provided feedback on the doctor's perspective she learnt the importance to have a BILS plan.

I had a prem baby, who stopped breathing at home, and I did not have a plan. So, all I could do was resus the child, but I did not have a plan. I did not know where we were going. (Female Participant Seventeen and Doctor)

BILS support training is emphasised to ensure parents keep their infants alive until they arrive at the healthcare facility.

So, from that, I believe it's very important what we are teaching our mummies now. It's a safety net, I knew how to perform CPR, and that's all you need, just to keep your baby alive till you get to the hospital. (Female Participant Seventeen and Doctor)

The perception of the HCP providing BILS on her way to a private hospital resulted in the private doctor implementing BILS training to preterm infant parents before discharge at the private hospital.

So yes, and because of us, I then told the private doctor, and because of that, they now give all their prem's moms resus training as well on discharge. (Female Participant Seventeen and Doctor)

This study revealed the personal perspective of an HCP who provided BILS to her own preterm infant. She learnt the importance of having a BILS plan. As a doctor and mother, the only thing she could do was to keep her infant alive until she arrived at the hospital. Her perception encouraged the private doctor at the private hospital to implement BILS training to the private preterm parents before discharge. The importance of BILS to parent's caregivers is thus emphasised.

Healthcare professionals are monitoring BILS training after discharge during follow-up visits at high-risk infants' clinics in the communities.

We write it up and we keep data to see if the baby has been re-admitted, and we follow up and see what the baby got readmitted with. If they have had resus training. Moms have resuscitated their babies the Sisters always feedback the information. They keep the stats for me. (Female Participant Sixteen and Doctor)

The HCP who is doing outreach at the high-risk follow up clinics in the community reported that they are monitoring the BILS training after discharge.

4.4.2.5. Subtheme: Challenges providing BILS training

The shortage of human resources resulted in only a few senior midwives providing BILS training. Midwives are equipped to provide BILS training; however, a quick turnover of midwives has been identified.

What is challenging you invest in getting people on-board, but then they leave for various reasons, promotions, better hours. So, we have got a very quick turnover. So, we invest in a lot of educational programmes with the new staff, but then they leave, and then you must start the whole process again. (Female Participant Seven and Midwife)

Health care professionals' viewpoints are that the shortage of human resources such as nursing staff members, resulted in cross covering of nursing staff members from other departments to work in the NNU.

Like KMC, again with shortages of staff, nowadays we are short a lot, then we get staff from other areas, from the wards, whoever can come and help and work in the neonatal unit. (Female Participant Five and Midwife)

Participants elaborated on the concerns that there is a lack of human resources such as nursing staff members to provide the BILS training. The senior midwives are mostly providing the BILS training, which resulted in an increased workload for them. Nursing staff members are developed professionally through educational programmes. However, a high turnover of nursing staff members was felt due to them leaving for different reasons such as promotions, better hours, and etcetera. Cross covering in the NNU of nursing staff members from other departments, such as postnatal wards in the hospital, has been done.

Healthcare professionals are concerned that midwives from the NNU are providing BILS training to preterm infant parents in the postnatal wards. Their views are that midwives in the postnatal wards might have low confidence levels as they are mostly caring for well infants in the postnatal wards.

So that is my question, why can't the ward Sisters not give the resus training? Why must they always ask the nursery Sisters? (Female Participant Twelve and midwife)

Maybe they don't feel as confident to do it because it's more our forte to do it than it is theirs. (Female Participant Eleven and Midwife)

Participants' views revealed that there is a concern that midwives from the NNU are providing BILS training in the postnatal wards as well. Their reasoning is that midwives who are working in the postnatal ward have low confidence levels to provide BILS training to parents as it is not their speciality.

The increased workload of midwives in the (NNU) has resulted in missed opportunities for BILS training in the absence of the midwife assigned to the KMC ward.

Then other challenges are, we have a busy neonatal unit. Some moms unfortunately do go home without the basic life support training, which we can't help for sometimes. But we try our best. (Female Participant Five and Midwife)

Gaps have been identified in the BILS training. Healthcare professionals' concerns include poor coverage of BILS training as caregivers who are not admitted to the KMC ward, often do not receive BILS training.

There are gaps in our training programme. I don't think we have complete coverage, the mothers who don't get admitted to the KMC ward often don't get basic life support training. (Male Participant 14 Doctor)

Both participants revealed concerns that BILS training missed opportunities are occurring for different reasons. The first participant's perception is that it is due to an increased workload in the NNU and the second participant's view is due to gaps in the training programme.

Time constraints have been faced by the midwives providing the BILS training as they are away from their workstations.

I often find after the resus training, obviously I can't leave ICU too long. (Female Participant Ten and Midwife)

The challenge is time. You know, you can't rush this in ten minutes, and there isn't always three quarters of an hour. (Female Participant Six and Midwife)

In brief again, barriers were identified on the BILS training provided. Increased workload in the NNU and lack of human resources resulted in missed opportunities for BILS training. Furthermore, low confidence levels of midwives working in postnatal wards resulted in midwives providing BILS training experiencing challenges with time constraints when BILS training is provided.

According to the HCPs there is a lack of equipment such as mannequins to provide the BILS training.

We use dolls. So, we have to sometimes bring our own children's dolls from homes to teach these moms, otherwise we don't really have anything to teach them on. Then our educational department will also provide us with different little dolls. (Female Participant Five and Midwife)

Healthcare professionals contend that there is one mannequin that is kept safely locked up; however, it could be used in different departments for BILS training.

So now we have a model, which I will borrow every now and then. It's a very precious doll. Because it's so expensive, we do keep it locked up. So, we do take it out when we do resuscitation, and it can float around. (Female Participant Seven and Midwife)

A request for more mannequins to provide BILS training is made by other HCPs.

More mannequins, more mannequins for every ward. (Female Participant Six and Midwife)

In contrast some HCP's stance was that mannequins are available and if needed then one is provided.

Well, they need a mannequin of sorts, which they do have, and usually we will come up with one if they can't. (Male Participant Fourteen and Doctor).

As has been noted, most HCPs' viewpoints were that a lack of mannequins is felt. In contrast, only a few HSPs views were that mannequins are available, yet other HCPs revealed that they had to use their children's dolls. A request for more mannequins was made.

Healthcare professionals' perspectives are that parents sometimes have cultural anxiety.

Challenges with the patients is sometimes a cultural anxiety. If I don't think about it, it's not going to happen, but if you talk about it, it might happen. (Female Participant Fifteen and Doctor)

In this study only one participant's view was that parents are experiencing cultural anxiety; however as stated before, parents felt confident and competent to provide BILS to their infants after BILS training was provided.

Challenges during an emergency with transport to healthcare facilities after discharge are felt by preterm infant parents.

Ambulances are issues. We constantly get that as an avoidable factor in our cases where babies have died, where there has just been a lack of transport or a delay. (Female Participant Sixteen and Doctor)

Similarly, in this study only one participant revealed that ambulance services are experiencing challenges to reach parents after discharge, which is an avoidable factor in cases where infants have died.

4.4.3. Theme Three: Supporting the BILS training programme

Under this theme, seven subthemes emerged inductively: developing a BILS video, importance of BILS training, developing individual BILS plans, implementing BILS support group on social media, implementing of BILS training at all birthing institutions, monitoring BILS training and including prevention and promotion strategies in BILS programme.

4.4.3.1. **Subtheme: Developing a BILS training video**

A recommendation made by HCPs was to develop a BILS training video to enhance the BILS training programme. Visualisation of BILS training ensures effective mass learning.

I have often thought if we could have a video made of that, to run every single day, and if we could have some social media thing that links to that, because that will start much more interest in the young mothers especially. (Female Participant Thirteen and Midwife)

Yes, because technology is at the forefront of everything nowadays. Some people learn more by watching than just listening to you talk. (Female Participant Eleven and Midwife)

Both participants agreed that a BILS video that is linked to social media will reach the greater community of young mothers as technology is at the forefront today.

Health care professionals' perspectives are that showing the video to the parents during the day will ensure ongoing BILS training.

I mean, even if it's through a video on a TV screen, in the ward. It is basic life support. It's one of the basic skills a mother should have. Especially with premature babies, and we have a captive audience, if there can be a video playing or a video in their room in the postnatal ward. I'm talking term babies even. (Female Participant Fifteen and Doctor)

Furthermore, visualisation accommodates educational levels and language barriers.

Often, it's hard, because the mom isn't fluent in English, so that is rather interesting sometimes for me, because maybe the mom is Xhosa or a foreigner. (Female Participant Thirteen and Midwife)

Healthcare professionals advocate a BILS video be produced to ensure ongoing mass training and to link it to social media to reach more parents. Visualisation accommodates different educational levels and language barriers.

4.4.3.2. Subtheme: Keep BILS training basic

A recommendation to keep the BILS training basic was made to ensure basic information empowers everyone. Health care professionals should consider all literacy and educational levels by providing basic BILS training.

Keep it basic, and to the level of their understanding. We don't know the moms and what is their literacy, their educational background. I mean corporate people deliver here, and we assume that they don't know these things, they don't understand. (Female Participant Seven and Midwife)

I have learnt that any information, irrespective of literacy and education level, if you keep it basic, it will be easy to understand everybody. (Female Participant Six and Midwife)

This study revealed that both participants' insights are that basic BILS training to parents accommodates all educational levels, regardless of their background.

Studies have shown that providing compressions first are more advantageous; however, the persuasion of the HCPs is that breathing is the most important step.

I think your basic life support needs to be as simple as possible. I mean, many studies have shown now that often to get the heart going fast, may be advantageous. Some people, some studies have shown more compressions per every breath is important. For me it's not what is most important. Keeping it as simple as possible and breathing is the most important thing. (Female Participant Fifteen and Doctor)

So, basically breathing for the baby, I think a lot of these lives could be saved. (Male Participant Fourteen and Doctor)

Both participants' stance in this study is that BILS needs to be as simple as possible and that breathing is the most important step for preterm infants to save their lives after discharge.

4.4.3.3. Subtheme: Developing individual plans

A strong recommendation made by HCPs was to ensure parents compile their own individual BILS plans before discharge, as a pre-thought-out plan is more likely to be successfully executed.

My other strong recommendation is, that individual plans be established that are tailored to the individual circumstances of the patients. The mother knows which facility she's going to take the baby to, which neighbour they're going to call, or who has the vehicle in the family, or to call an Uber. Who is going to be doing the life support, and who is going to be arranging the transport. If you have a pre-thought-out plan, you're more likely to get it right. (Male Participant fourteen and Doctor)

So, we've been teaching basic life support for a long time to all our mummies in KMC. A has really drilled into them, what do you do when your child stops breathing. That's the first thing, but before when the child stops breathing, you need a plan. He wants them to have a plan. So, who are you going to call, which hospital you are going to go to and who is going to take you there? Do you call the ambulance, do you call someone to take you there quickly? You need a plan. (Female Participant 17 and Doctor)

In this study both participants are advocating the importance for parents to have an individual BILS plan. The plan should include; parents know how to initiate BILS, who they going to call, which healthcare facility they will take the infant to and what transport arrangements they going to make. The first participant advised that roles should also be assigned as to who will be providing BILS and who will call for transport. A pre-thought-out plan is more likely to manage an emergency successfully.

4.4.3.4. Subtheme: Implementing BILS Support groups on social media

Health care professionals' perceptions are that a BILS support group on social media will provide a communication platform to parents of preterm infants. Parents could share their perspectives after discharge on a BILS support group. Furthermore, experts will be providing evidence-based BILS advice to the parents on the support group.

If it can be with the other moms, they can also share their perspectives that they have been through. I mean, that's also a kind of support, because it empowers her, it encourages her. So, with the support groups on Facebook or whatever. The experts, the people that give the training. If they see there are any questions and you just respond evidence-based things. (Female Participant Eleven and Midwife)

HCPs are suggesting support groups, as parents normally have good interaction with the midwives after the training and they ask a lot of questions.

I often find after the resus training, then there is often a good interaction and they will ask what about who and what about this and what about that. So, there is a need for maybe a support group as well in amongst the training as well, because they feel more relaxed to ask us unusual questions. (Female Participant Ten and Midwife)

In this study both HCPs suggested that support groups should be established on social media to support parents after BILS training was received. The first participant's perception is that the parents could share their perspectives with each other to support each other. In addition, HCPs could provide evidence-based advice. Furthermore, the second participant shared that parents are more relaxed after the training to ask uncommon questions.

4.4.3.5. Subtheme: Implementing of BILS training to all birthing institutions

According to the HCPs, BILS training should be implemented at all birthing institutions to ensure empowerment of all parents of preterm and term infants.

I think we need to systemise it so that we get better coverage, so that no mother leaves, or no baby leaves without the caregiver having had training. (Male Participant Fourteen and Doctor)

A suggestion is made that BILS training should be provided at all healthcare facilities where perinatal services are offered, even if a video is used. BILS involves basic skills that every mother should have.

I think all people should be doing it at all birthing institutions. I mean, in an ideal world we will teach all our mothers who stay in for one night. I mean, even if it's through a video on a TV screen, so in the ward. But everyone should have exposure, it is basic life support. It's one of the basic skills a mother should have. (Female Participant Fifteen and Doctor)

In this study, participant one's insight is that BILS training should be systemised so that every parent receives BILS training before discharge. In addition, participant two says BILS is a basic skill for every mother, therefore, all healthcare facilities offering perinatal care services should provide BILS training to all parents before discharge, even if BILS is taught via a video to reach everyone.

Furthermore, all healthcare workers should be equipped with BILS training. The norm is that BILS training is always provided by midwives, yet registered assistant nurses are assisting midwives when BILS is provided to infants.

With resuscitation, we always try to focus more on the more senior staff, which is the professional nurses. But the registered assistant nurses have shown us that it starts with them, because they are the people that assist us to do that resuscitation properly. So, I feel very strongly that we should involve each-and-every person with resuscitation. (Female Participant Seven and Midwife)

All categories of staff members should be equipped to provide BILS. Porters and general assistants are also caregivers who have children.

And we are all parents, so you could use it if you're a cleaner or a porter, you could use it at home for your child, or a neighbour. (Female Participant Eight and Midwife)

In conclusion, HSPs recommend that all categories of healthcare workers be equipped to provide BILS, including porters and general assistants. Registered assistant nurses should also be included in BILS training as they are always involved in assisting midwives when BILS needs to be provided to infants.

4.4.3.6. Subtheme: Monitoring of BILS training

HCPs urge that monitoring of effectiveness of BILS training after discharge of preterm infants be done. Healthcare professionals should at all health care facilities, capture

and provide data to ensure ongoing monitoring of the effectiveness of BILS training provided.

Yes, post discharge. I do know we do have a lack of getting feedback back, the (MOU) will feed it back to me, but I will battle sometimes to get the information back from the bigger hospitals, and I think that is something that we need to look at in the future. Mortality is easy, but I don't think morbidity is easy to capture. (Female Participant Sixteen and Doctor)

The participant is doing outreach at high-risk follow-up clinics in five communities where the effectiveness of BILS training is monitored and evaluated. However, the HCP finds it challenging to receive information from bigger hospitals about parents who provided BILS and the causes of the life-threatening event. A need for to provide information on morbidity of preterm infants is identified to ensure monitoring and evaluation of the BILS training parents received before discharge.

4.4.3.7 Subtheme: Implementing prevention and promotion strategies in BILS training programme

To ensure an improvement of the BILS training programme an endorsement was made to include the prevention and promotions strategies of the Department of Health into the BILS training programme.

Well, I think we need to review the curriculum, to check that all aspects of promotive, preventive and therapeutic are included. Prevention and promotion strategies such as; advantages of breastfeeding and advantages of kangaroo mother care should be included. Other strategies to be included are the infection prevention and control strategy as well as the therapeutic strategy to identify danger signs. (Male Participant Fourteen and Doctor)

Furthermore, it is encouraged that all mothers get a KMC wrap from the start to ensure ongoing KMC is provided. The perception is that infants are exposed to inhalation of smoke and become apnoeic while they are lying on a bed.

Every mother at birth gets a wrap, a free wrap. So that the mothers can (KMC) from the word go, and when they go home, they continue KMC and then there will be less resus to do. I think a lot of resus happen because the babies lie on the bed, or mothers smoke and don't change their clothes. That's my

recommendation, that a wrap should really be part of a service, like an incubator. (Female Participant Thirteen and Midwife)

This study revealed that participant one's directives are that the prevention and promotion strategies such as breastfeeding, KMC and infection prevention be included in BILS training. Participant two suggested all caregivers receive KMC wraps at no cost to ensure parents start providing KMC from the beginning. A concern raised is that infants become apnoeic, as caregivers who are smoking, expose the infant to the smell of smoke or they are lying on the bed. Apnoea could be prevented or minimised if parents are taught all the above-mentioned strategies.

4.5. Summary

The findings of the qualitative single case study with two embedded units of analysis were described in this chapter. The viewpoints of a total of seventeen caregivers of preterm infants who were involved in the BILS training were described in-depth.

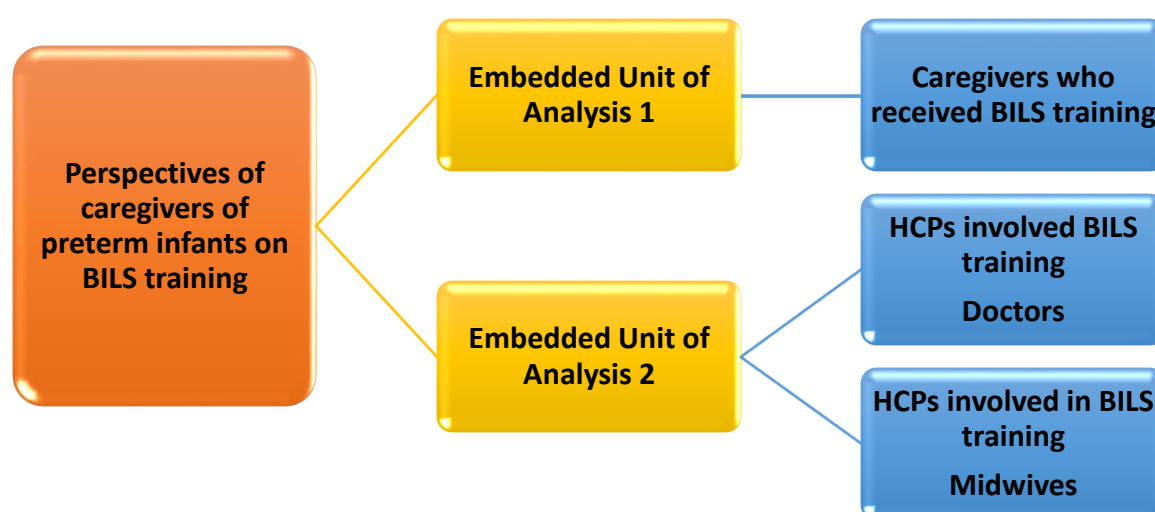


Figure 4.1: Three Principle Themes on the phenomenon

The findings of the in-depth individual interviews of the parents of preterm infants who received the BILS training were that they had learnt about themselves and were empowered with BILS knowledge and skills. Parents applied the knowledge and skills after discharge by managing emergencies successfully. These parents' views are that they are empowered to empower others. They initially felt anxious; however, felt

competent, confident and reassured after they received BILS training. The findings of the in-depth interviews of the HCPs, doctors and focus group discussions of the midwives, who were involved in the BILS training, justified the need for BILS training to be provided to caregivers of preterm infants. Positive feedback was provided by HCPs about parents that provided BILS training after discharge. Barriers to BILS training were identified and discussed. Suggestions were made by HCPs to enhance the BILS training programme

4.6. Conclusion

The findings of the perspectives of all the caregivers who received the BILS training is revealed in this chapter under three themes: BILS Training, Discharge Information and Supporting factors. Furthermore, the findings of the perspectives of HCPs who were involved in the BILS training were revealed under three themes: motivation for BILS training, providing BILS training and supporting factors for BILS training programme.

In Chapter Five, the discussions, conclusions and recommendations, limitations, future research and dissemination of the single case study research will be presented.

5. CHAPTER FIVE

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1. Introduction

The previous chapter discussed the results and findings of this study with reference to participants' perceptions. This chapter will discuss the findings with reference to available literature and draw conclusions based on the discussion. Further, the researcher will make recommendations based on the findings and discussions of the study. Then the discussions on whether the objectives and goal of the study were achieved will be discussed.

5.2. Discussion

The aim of the single qualitative case study was to explore the perspectives of caregivers of preterm infants on the BILS support training at a public secondary hospital. There were two embedded unit of analysis which included parents who received the BILS training before discharge, and the HCPs who were involved in the BILS training. These HCPs were doctors and midwives.

The study problem was that preterm infants are experiencing long hospitalisation periods of two to three months. Sadly, these preterm infants are at risk of life-threatening events and mortality soon after discharge (WHO, 2017:1). Preterm infants are dying within the first week after discharge (WHO, 2017:1). International policies and the Western Cape Department of Health kangaroo-mother-care policy advocate that parents of preterm infants receive BILS training before discharge, (Brannon et al., 2009:33; WCDOH, 2011:48). Yet, the BILS training is not provided at all birthing institutions. (Wates, 2017).

Perspectives of the caregivers identified limitations and supporting factors to enhance the BILS training. These barriers and supporting factors will be discussed to justify the directives to enhance the BILS training at the Public Secondary Hospital, in the Metropole of Cape Town, Western Cape, South Africa. Certain views of the parents and HCPs corresponded with each other, yet, differentiation of certain views was also identified.

The objectives for the study were;

- RO 1** To describe the perspectives of caregivers of preterm infants who received the BILS skills training before discharge in a public hospital in the Cape Town Metropole in the Western Cape, South Africa.
- RO** To determine the perspectives of healthcare professionals who are involved with discharge readiness of preterm infants in a public hospital in the Cape Town Metropole, on the BILS skills training.
- RO 3** To identify barriers and supporting factors about the BILS skills training programme for the caregivers of preterm infants before discharge in a public hospital in the Cape Town Metropole.

The objectives for this study were met based on the findings of this research. This chapter will base the discussions on the objectives, findings and the literature review to support the perspectives that arose from the study.

5.3. Perspectives of parents of preterm infants

The views of parents who received the BILS training before discharge were that they were empowered with BILS knowledge and skills to save their infants' lives and help others in the communities. Bracht et al. (2013:115) and Jefferies (2014:31) contend that providing education such as BILS skills, will ensure that caregivers/parents are well prepared before the preterm infant is discharged home.

Parents reflected on BILS training provided and revealed that the training method used was instruction and demonstration. Visualisation on the demonstration resulted in effective learning. They felt empowered and reported that negative preconceptions about public hospitals have changed. Brannon et al. (2009:133) confirm that parents of preterm infants, who received BILS training before discharge and who had instructor-led training, had skills assessments of ventilation and chest compressions, which were rated 'good', 'fair' or 'fail'. To pass, these parents had to rate good or fair in all skills. The study revealed that nine (9) out of 13 parents who received instructor-led training passed and were able to effectively provide BILs training. This study also revealed that the parents who received the BILS training were able to provide

breathing and compressions to their preterm infants during life-threatening events after discharge.

Parents in this study reported that their infants stopped breathing after discharge and that they provided BILS to their infants. Further, sharing their perspectives with other parents of preterm infants after discharge included being confident enough to get support, which ensures that they are supporting each other after discharge. These parents felt confident and empowered to empower friends and family members with BILS knowledge and skills. These findings were confirmed by Bracht et al. (2013:115) and Jefferies, (2014:31), who confirmed that these parents enhanced their problem-solving skills as well as managed their anxiety levels to prepare them to care for their infants after discharge.

Empowering other care givers with BILS support discharge information was one of the subthemes that emerged. Trained parents revealed that they received BILS pamphlets which they could refer to while at home as one of the BILS steps. The parents in this study shared the BILS pamphlets with their family, nannies and friends. These pamphlets were guidelines to update parents with BILS information and to share the information with family, nannies and friends. According to Knight, et al. (2013:14) the discharge information such as a “CPR Anytime Kit™” is a flexible, sustainable method for parents of preterm infants to watch the video again after discharge to ensure BILS knowledge and skills retention of parents. In addition, Knight et al. (2013:14) also stated that, according to their study, the parents of preterm infants shared the videos with their family and friends to equip more lay people to do BILS. Further, according to the discharge information provided to the parents in this study, it is similar to the findings of Knight et al., that the empowered parents were able to use their knowledge and skills acquired to help the greater community with BILS skills after discharge.

Both caregivers and the HCPs indicated that the parents felt emotionally empowered. They initially felt anxious, but then empowered, and confident and reassured after BILS training was received. This allowed them to cope with the emotional components emerging from the BILS. Written feedback from parents revealed that the BILS skills training significantly reduced the caregivers’ anxiety levels (Knight et al., 2013:14). This study’s findings corresponded with Knight et al. (2013:14) in that caregivers initially felt anxious yet felt empowered and confident after BILS training was provided.

5.4. Healthcare Professionals' Perspectives

Healthcare professionals' justifications for BLS training are that smaller preterm infants are discharged at a weight of 1750 grams. These preterm infants are clinically well on discharge. However, the systems of these infants are still immature. According to literature, in the past, preterm infants were discharged at a weight of 2000 grams (AAP, 2008:3). According to Jefferies (2014:32) and AAP (2008:3), discharge readiness is recognised when the preterm infant can maintain his/her body temperature, able to feed well, is gaining weight steadily, controls breathing and has respiratory stability and parents are involved and trained to care for the infant after discharge. However, they are still prone to apnoea after discharge. Preterm infants are at higher risk to have sudden infant death syndrome (SIDS). Preterm infants are also at greater risk to contract community acquired infections due to their immature immune systems.

Premji, Young, Rogers & Reilly (2012:61), reported that the immaturity of the autonomic brain stem can result in sudden infant deaths of preterm infants. AAP (2008:3) agrees that the respiratory immaturity of preterm infants could be up to 44 weeks' gestational age. Evidence obtained in this study asserts that even though preterm infants' conditions are healthy on discharge, they are still prone to apnoea, infections and (SIDS).

HCPs revealed that preterm infants receive expensive hospitalisation over two to three months however, some preterm infants die soon after discharge. According to the WHO (2017:1), unclean water, sanitation and poor hygienic circumstances are the main causes of death of the preterm infants following discharge. Approximately 270 000 infants and preterm infants die within the first month of life due to respiratory infections caused by smoke inhalation and diarrhoea due to poor hygiene practices.

At the time of discharge the infants go to poor socioeconomic circumstances where they are exposed to environmental hazards such as air pollution, smoking, and parents on substance abuse which could result in neglect. WHO (2017:1) substantiated that polluted environments such as polluted air and water are dangerous to preterm infants due to their immature, developing organs and airways, causing pneumonia and diarrhoea. The risk factors of preterm infants after discharge were elaborated on by the HCPs, which reinforced and justified the need for Parents of preterm infants and

community healthcare workers to be equipped with BILS training. Doherty et al. (2016:673) advocate that the scope of community healthcare workers be increased in South Africa to reduce the infant mortality rate after discharge. Healthcare professionals suggested BILS training to parents of preterm infants and community health workers in order to prevent infant mortality soon after discharge and to optimise expensive healthcare rendered.

Healthcare professionals reflected on the BILS training and revealed information shared with parents such as the importance of BILS training among others. The HCPs used instruction and demonstration of BILS as the training method. Furthermore, BILS training is also provided by the midwives in the postnatal wards with parents whose preterm infants conditions are stable enough to be with the parent in the postnatal ward.

According to Judith, Gooding, Cooper, Arianna & Blaine (2011:25), group and individual sessions of BILS skills training and demonstrations can be provided by midwives to parents of preterm infants during their stay in hospital. Medical information can be shared in layperson's terms to enhance retention of knowledge. Group sessions of BILS training were provided to parents of preterm infants in the kangaroo mother care ward in the neonatal unit (NNU). Individual BILS training sessions are prescribed by doctors for parents whose infants had life-threatening events such as recurrent apnoea spells in the NNU. BILS training is provided by midwives who are working in the NNU (Judith et al., 2011:23; Purdy et al., 2015: S24).

Family members who are with the parent at the time of BILS training are also included in the training to ensure the primary parent's support structure. According to Jefferies (2014:34), HCPs should provide education to the parents from admission to increase their knowledge and skills, increase their confidence levels and decrease stress. Evaluation of BILS knowledge before and after training was done to build on parents' knowledge, ensure interaction and after BILS training to test knowledge retained. Evaluation of parents whose infants had life-threatening events before discharge is done informally by quizzing these parents to ensure that they are empowered to provide BILS after discharge.

Brannon et al. (2009:34) advocate that a self-instruction video could also be watched prior to instructor-led BILS skills training as a supplemental learning tool. This study

validates previous studies that method of instruction and demonstration ensure effective learning. Including other family members in BILS enhances the support structure of the primary parent. Evaluation of the BILS knowledge and skills are important to determine the effectiveness of BILS provided.

The HCPs in this study advocated that BILS training be documented for monitoring purposes. According to AAP, (2011:6) there is need for self-assessment, monitoring and evaluation of the BILS programme and capturing of statistics. The HCPs confirmed that pamphlets with BILS training information was provided as discharge information to the parents.

Further, documentation of BILS training could ensure data for monitoring at the high-risk infant's clinic in the communities. HCPs confirmed information shared by parents that BILS discharge information, such as pamphlets, ensures ongoing education and update parents with BILS information. These pamphlets are available in five languages to accommodate language barriers. Pamphlets are provided to parents in their preferred language.

In conclusion, above HCPs' views on risk factors of preterm infants such as infections, apnoea, SIDS and socioeconomic circumstances after discharge are discussed. Furthermore, HCPs reflected on BILS training provided to caregivers before discharge. The findings of this study provided evidence that empowering parents with BILS skills will optimise the expensive healthcare preterm infants received. Parents's were able to identify danger signs and saved their infants' lives. BILS is cost-effective and feasible.

5.4.1. Barriers and Supporting factors

The third objective was to identify barriers and supporting factors regarding the BILS skills training programme for the parents of preterm infants before discharge in a public hospital in the Cape Town Metropole. These barriers were identified by parents and the HCPs. Firstly, the influence of language barriers and educational levels were challenges that impacted on understanding and applying the knowledge and skills learnt optimally. Parents' advice to optimise the training was that the BILS training should remain unchanged but basic enough to accommodate all educational levels and prevent information overload. Brannon et al. (2009:133) reason that parents of

preterm infants who receive pre-discharge education about aspects such as BILS, and education on other topics, could become overwhelmed with an overload of information which could result in less effective learning.

Healthcare professionals advised that a BILS training video be produced to show to parents in all departments (Knight et al., 2013:14). Knight et al. also concurred that the “CPR Anytime Kit™” is an effective standardised self-instruction video kit method that is an alternative to instructor-led training in low-resource settings that provides BILS skills training to parents of preterm infants before discharge. However, Brannon et al. (2009:32) argue that preterm infants’ parents need to watch an instructional BILS skills training video before instructor-led training to ensure good retention of skills and to accommodate different education levels of the parents.

Visualisation of BILS training accommodates language barriers. According to Brannon et al. (2009:133), the utilisation of a video assists to educate the parents accommodate parents with language barriers. However, visualisation ensures effective learning and parents translated the information for others after the BILS training in their preferred language. Brannon et al. (2009:38) also contend that video preparation is cost effective and the parents can watch it at a time most suitable for them. However, both the video and instructor-led training should be offered as the video alone will not be effective. This study’s finding related to literature that visualisation of BILS accommodates language barriers and all educational levels. Parents called compressions “pressing” or “punch,” as they understood it. This did not stop them from providing BILS effectively to the infants even without using the correct names provided by the training.

Healthcare professionals also revealed that a lack of human resources such as midwives to provide the BILS training was a challenge. Senior midwives who are working in the (NNU) high care and intensive care unit need to do BILS training in the absence of the midwife who is assigned to the kangaroo mother care ward. Furthermore, these senior midwives also need to provide BILS training to parents of preterm infants in the postnatal wards. According to AAP (2011:6), availing a budget for preparation of training (e.g. obtaining equipment such as mannequins) and developing training plans to ensure capacity building of midwives through continuous

mentoring is encouraged. Without adequate midwives and resources, it is difficult to accurately provide appropriate training.

This study indicated that the midwives were removed from their work stations therefore experiencing time constraints during BILS training as they have only a short period of time to be with the parents. This further increased workload in the NNU, sometimes resulting in missed opportunities to provide BILS training to some parents before discharge. Knight et al. (2013:9) contend that training barriers posed risks of BILS skills training before discharge being inconsistent and the effectiveness being short term.

These midwives' persuasions are that the midwives who are working in the postnatal wards should also be equipped to provide BILS training to parents as they might have low confidence levels. Knight et al. (2013:9) assert that the lack of time, discrepancy of nursing skills, difference in confidence levels and different instruction methods could prevent standardised BILS training to parents of preterm infants.

According to AAP (2011:6), to ensure the sustainability of the BILS training, capacity building such as continuous mentoring of midwives could be done. Therefore, the senior midwives are mentoring the midwives in the wards during BILS training of parents. Newly qualified midwives who are community service practitioner's, are also receiving BILS training during their induction programme, to assist and provide BILS training to parents.

A lack of mannequins to provide demonstrations to parents during group sessions or individual sessions of BILS training was identified. Brannon et al. (2009:138) argue that BILS skills are psychomotor skills, therefore parents need to practice more on mannequins to ensure that they are competent to provide BILS skills to preterm infants after discharge. AAP (2011:6), indicates that a budget should be made available to procure training equipment, more specifically mannequins. HCPs indicated that more mannequins for each ward should be procured to ensure BILS training resources are available.

Healthcare professionals identified cultural barriers and revealed that parents sometimes do not want to think about providing BILS training. Bracht et al. (2013:15) suggest that person- or family-centred care is advocated in neonatal units (NNU's) by

involving and educating parents to find their own strengths, to confidently take care of their infants after discharge. It is a strategy of the WCDoH (2016:1) to ensure person-centred care which includes culturally sensitive care.

Further, parents are experiencing transport problems during an emergency after discharge. Therefore, the suggestion was that the parents need to develop their own individual BILS plans before discharge. If parents have an individual plan according to their own circumstances, then they will be able to execute the BILS successfully during an emergency (AAP, 2008:8)

The individual BILS plan should include: who they call for help; what transport arrangements will be made in advance; which healthcare facility they will take the infant to during the day or night; who will be providing the BILS training and who will make transport arrangements. Healthcare professionals suggested that preventive and promotive strategies such as advantages of breastfeeding and kangaroo mother care be included in the BILS training.

Brannon et al. (2009:133) indicate that the parents of preterm infants who receive pre-discharge education about aspects such as BILS, and education on other topics, could become overwhelmed by an overload of information which could result in less effective learning. The findings of this study are unique to the parents and HCPs at the public secondary hospital in Cape Town, South Africa. Parents were spending up to eight hours per day caring for their preterm infants whilst receiving daily education by healthcare professionals in NNUs. This could easily lead to fatigue and ineffective learning.

Knight et al. (2013:14) further cite various studies (Dracup, Moser, Doering, & Guzy, 1997a; Dracup et al., 1997b, 1998; Moser et al., 1999; Schlessel et al., 1995, in Knight et al., 2013) who stated in previous studies that parents managed to learn BILS despite anxiety. Furthermore, written feedback from parents revealed that the BILS skills training significantly reduced their anxiety levels (Knight et al., 2013:14). Healthcare professionals contend that parents are initially anxious, however they felt empowered to provide BILS to their infants after discharge. Therefore, it is important that HCPs educate caregivers to identify danger signs to act and provide BILS after discharge. Healthcare professionals provided positive and negative feedback that parents, who provided BILS to their preterm infants after discharge, arrived at the health care

facilities without loss of circulation in their infants. However, parents are also reporting that the only negative feedback is when infants are still dying soon after discharge.

In conclusion, the above barriers such as lack of midwives to provide BILS training, time constraints and lack of mannequins, transport problems after discharge and cultural anxiety were identified and discussed. Healthcare professionals suggested a need to systemise the BILS training and to prevent further poor coverage of BILS training to parents. The AAP (2011:6) guidelines have a framework to implement a sustainable BILS programme which consist of the following: a national proposal to develop policies and guidelines for strategic planning, availing a budget for preparation of training (e.g. obtaining equipment such as mannequins), finding master trainers and developing training plans (capacity building, continuous mentoring, supervision and self-assessment, monitoring and evaluation of the programme), capturing of statistics and lastly quality assurance by including regulations, standardized operational plans and compliance. This study's findings are coherent with previous literature.

5.5. Limitations of the study

Specific limitations faced during the study were that diversity was compromised as only black, white, and coloured participants met the inclusion criteria during the time of recruitment for data collection. Normally all races such as indian, white, coloured, black parents with preterm infants receive neonatal and perinatal care at the hospital. However, no indian and white parents were available at the time of data collection.

Another limitation is that the researcher is employed at the hospital and was a key roleplayer with the re-implementation of the BILS training programme in 2009. The researcher adhered to all the ethical considerations and scholarly rigour during the research process.

“The inductive reasoning moves from the specific to the general.” This is standard in this qualitative single case study and could result in unconfirmed generalisations which might need further research for confirmation (Rule & John, 2011:98).

The researcher was a novice researcher and realised that more probing could have been done during in-depth semi-structured interviews with the participants to obtain more information.

The researcher takes cognisance that the findings of this single case study cannot be generalised to the entire population of parents and HCPs involved in BILS as it could only make valid claims and patterns to the specific case (Rule & John, 2011:105). However, Rule & John (2011:105) argue that the single case study approach was appropriate to ensure an in-depth and comprehensive understanding of the case/phenomenon.

5.6. Conclusions

The key findings of this qualitative single descriptive case study with two units of analysis to obtain the perspectives of parents of preterm infants who received the BILS training before discharge, and HCPs who were involved in BILS training, have been reached. The study revealed that parents are empowered to save their infants' lives. These parents are also equipped to empower family members and communities.

The problem is that preterm infants are hospitalised for long periods of between two to three months and sadly die soon after discharge. Healthcare professionals involved in the BILS training justified the need for BILS training to all parents of preterm infants. Smaller preterm infants are discharged in stable conditions, yet their systems are still immature. These preterm infants are discharged to socioeconomic circumstances that pose environmental hazards such as inhalation of smoke and unhygienic circumstances. Preterm infants are still prone to apnoea, infections and SIDS. BILS training for parents of preterm infants is strongly advocated to optimise expensive healthcare rendered and to decrease preterm infant mortality soon after discharge.

Barriers and supporting factors for the BILS training, which have been identified by parents and HCPs have been discussed in-depth in chapter 5. Therefore, the key research questions of both units of analysis in this descriptive single case study have been answered and the research problem has been accepted. The recommendations from both units of analysis will follow.

5.7. Recommendations

Recommendations for the study were made by the researcher based on the findings and discussions related to the literature.

5.7.1. Perspectives of parents who received the BILS training

Parent's insights were to keep the BILS training basic as it accommodates all educational levels, language barriers and could prevent information overload. Furthermore, another recommendation was to procure automated mannequins to create real life situations which will ensure effective BILS learning of parents of preterm infants before discharge.

5.7.2. Insights from Healthcare professionals

HCPs' directives were to provide BILS training to parents of all infant preterm and full-term infants, as the infant mortality statistics revealed that preterm and full-term infants are at risk of life-threatening events after discharge. Feedback provided from HCPs was that parents were equipped to provide BILS to their preterm infants successfully after discharge.

A second suggestion from HCPs is to produce a BILS video to do mass training at clinics, antenatal wards and postnatal wards. Visualisation of BILS training ensures ongoing education and accommodate all educational levels and language barriers. Furthermore, parents' BILS information could be reinforced by watching the video more than once.

A third directive from HCPs was to implement individual BILS plans before discharge, to assist parents to develop their own individual BILS plan: who are they going to call for help, what transport arrangements are made with a family member or a taxi; which healthcare facility they going to take their infant to during the day or night and assign roles as to who will be providing BILS to the preterm infant and who will arrange transport.

A fourth directive from HCPs was to ensure that preventive and promotive perinatal strategies such as advantages of breastfeeding, kangaroo mother care and prevention of infection, are reinforced before BILS training to prevent apnoea or infection. Education of parents starts on admission. A discharge checklist could include all the recommendations and proof of documentation that the directives were implemented and adhered to.

5.8. Barriers and supporting factors identified

The first directive from HCPs was made to systemise the BILS training to address all gaps that have been identified in the BILS training. The systemisation of the BILS training includes involving all stakeholders to ensure strategic planning and to ensure the sustainability and feasibility of the BILS training.

The second directive was to allocate a budget for the procurement of enough mannequins for BILS training to ensure demonstrations are provided effectively. Each department such as the postnatal wards and NNU, should have enough mannequins to ensure demonstrations which enhance visualisation for effective BILS training.

The third directive was to ensure education and training of all midwives and nursing staff members to provide BILS training to parents to prevent missed opportunities and to alleviate the workload of senior midwives. Midwives in postnatal wards should provide BILS training to parents to ensure that all parents receive BILS training before discharge.

The fourth directive was to ensure that the BILS training become part of the discharge plans of all parents of preterm and full-term infants in the neonatal units and postnatal wards. BILS support training empowers parents, which includes family members to enhance her support systems and to save their infant's life after discharge.

The fifth directive was to implement support groups on social media for parents to share their BILS perspectives and to encourage each other. Evidence-based advice could be provided to the parents by the experts who provided BILS training. Parents could also support and encourage each other on the support group.

The sixth directive was to ensure documentation of BILS training in a training register, folder of the infant, and in the Road to Health Booklet for monitoring and evaluation purposes. Monitoring and evaluation of the effectiveness of BILS is important to determine if parents have provided BILS support after discharge and to determine the cause of the life-threatening event.

The seventh directive was to provide discharge information such as pamphlets to ensure ongoing education for parents and empowerment of communities. Parents

revealed that they shared BILS information with family members to ensure their support structure.

The eighth directive was to develop BILS pamphlets in Shona to provide the pamphlets in the preferred language of parents as it is currently available in five languages, including French, Afrikaans, English isiXhosa and Arabic.

The researcher's recommendation is that short video clips be produced of the steps of BILS training. These clips could be sent via social media to every parent after BILS training was received to ensure ongoing education. Parents will be able to send the video clips to family and friends which could result in educating the greater communities with BILS skills.

My recommendation is also that BILS training should become part of every new-born infant's discharge plan. Therefore, BILS training should be integrated in discharge preparation of all new-born infants at all birthing institutions.

I recommend that feedback on the BILS training should be done at neonatal advocacy meetings or clinical management meetings to keep all HCPs informed about the progress of the enhancement of the BILS training and to manage issues arising.

Lastly, to standardize the BILS training programme to be implemented by all stakeholders such as policy makers, academics at universities, colleges, primary, district, secondary and tertiary levels of care.

5.9. Dissemination of research findings

A detailed research report will be sent to the senior management, clinical heads, nurse managers and participants of the public secondary hospital where the research was conducted. They will be informed about the barriers identified in BILS training and directives provided to enhance the BILS training programme.

A Research Report will be sent to the WCDoH policy makers and Strategy and Health Support departments to inform them about the gaps identified and directives for practice. Presentations will be done at the public secondary hospital and other healthcare facilities to inform the HCPs about findings of the study.

Presentations will be done at the Annual Research Provincial Health Day and the District Research Day to ensure the greater community is informed about the directives to enhance the BILS training.

Presentations will also be done at Perinatal Priorities Conferences, Midwifery symposiums, Kangaroo Mother Care Conferences to ensure the all HCPs are informed on the BILS directives nationally. The researcher will be writing articles to be published in peer-reviewed journals.

Lastly presentations will be done in community halls to inform parents in communities about the BILS training study and to empower more parents to save their infant's life.

5.10. Future research

Future research could be done to replicate the descriptive single case study at different settings, such as at public secondary and tertiary hospitals to confirm generalisations made in this study.

Future research on the effectiveness of standardized BILS skills training programme to parents of preterm and term infants. A replication of the descriptive case study at healthcare facilities in rural settings of South Africa.

Lastly future research of the effectiveness of individual BILS plans for parents of preterm infants.

6. REFERENCES

- American Academy of Pediatrics, 2016. Helping Babies Breathe Training Program—A neonatal resuscitation curriculum for resource limited circumstances. 2011.
- Stark, A.R., Adamkin, D.H., Batton, D.G., Bell, E.F., Bhutani, V.K., Denson, S.E., Martin, G.I. and Watterberg, K.L., 2008. Hospital discharge of the high-risk neonate committee on fetus and newborn. *Pediatrics*, 122(5), pp.1119-1126. [Accessed 2017, May 16].
- Atkins, D.L., Berger, S., Duff, J.P., Gonzales, J.C., Hunt, E.A., Joyner, B.L., Meaney, P.A., Niles, D.E., Samson, R.A. and Schexnayder, S.M., 2015. Part 11: pediatric basic life support and cardiopulmonary resuscitation quality: 2015 American Heart Association guidelines update for cardiopulmonary resuscitation and emergency cardiovascular care. *Circulation*, 132(18 suppl 2), pp.S519-S525.
- Dowling, D., Barsman, S.G., Dowling, D.A., Damato, E.G. and Czeck, P., 2015. Neonatal nurses' beliefs, knowledge, and practices in relation to sudden infant death syndrome risk-reduction recommendations. *Advances in Neonatal Care*, 15(3), pp.209-219.
- Bracht, M., O'Leary, L., Lee, S.K. and O'Brien, K., 2013. Implementing family-integrated care in the NICU: a parent education and support program. *Advances in Neonatal Care*, 13(2), pp.115-126.
- Bracht, M., O'Leary, L., Lee, S.K. and O'Brien, K., 2013. Implementing family-integrated care in the NICU: a parent education and support program. *Advances in Neonatal Care*, 13(2), pp.115-126. [Online]. Available: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2666859/> [Accessed 2017, April 20].
- Brett, J., Staniszewska, S., Newburn, M., Jones, N. and Taylor, L., 2011. A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of preterm infants. *BMJ open*, pp.bmjopen-2010.
- Brink, H., Van der Walt, C. and Van Rensburg, G., 2006. *Fundamentals of research methodology for health care professionals*. Juta and Company Ltd.
- Personal communication: Booy's, G. 2018. Nurse Manager. *Duty Roster-Nursing Service August 2018*, Mowbray Maternity Hospital, Cape Town, South Africa [Unpublished]
- Burns, N. and Grove, S.K., 2010. *Understanding Nursing Research-eBook: Building an Evidence-Based Practice*. Elsevier Health Sciences.

- Cape Town: Children's Institute, University of Cape Town. Department of Health, 2014. Protecting, Promoting & supporting Exclusive & Continued Breastfeeding. A Breastfeeding Course for Health Care Provider, Pretoria, Republic of South Africa.
- Doherty, T., Kroon, M., Rhoda, N. and Sanders, D., 2016. Ending preventable child deaths in South Africa: What role can ward-based outreach teams play?. *South African Medical Journal*, 106(7), pp.672-674.
- Emanuel, E.J., Wendler, D., Killen, J. and Grady, C., 2004. What makes clinical research in developing countries ethical? The benchmarks of ethical research. *The Journal of infectious diseases*, 189(5), pp.930-937.
- Grove, S.K. and Gray, J.R., 2018. *Understanding nursing research: Building an evidence-based practice*. Elsevier Health Sciences.
- Houghton, C., Casey, D., Shaw, D. and Murphy, K., 2013. Rigour in qualitative case-study research. *Nurse researcher*, 20(4).
- Jamieson, L. and Lake, L., 2013. *Children's Act guide for health professionals*. Children's Institute, University of Cape Town.
- Jefferies, A.L., 2014. Going home: facilitating discharge of the preterm infant. *Paediatrics & child health*, 19(1), pp.31-36.
- Judith, B.A., Gooding, S., Cooper, L.G., Blaine, A.I., Frank, L.S., Howse, J.I., & Berns, S.D., 2010. Family-centred Care in the Neonatal Intensive Care unit: Origins, Advances, Impacts.
- Knight, L.J., Wintch, S., Nichols, A., Arnolde, V. and Schroeder, A.R., 2013. Saving a Life After Discharge: CPR Training for Parents of High-Risk Children. *Journal for healthcare quality*, 35(1), pp.9-17.
- Lopez, G.L., Anderson, K.H. and Feutchinger, J., 2012. Transition of premature infants from hospital to home life. *Neonatal network: NN*, 31(4), p.207.
- Maconochie, I., Bingham, B. and Skellett, S., 2015. Paediatric Basic Life Support. *Resuscitation Council (UK), London*. <https://www.resus.org.uk/resuscitation-guidelines/paediatric--basic-life-support>. [Accessed 2017, May 19].
- Marín Gabriel, M.A., Llana Martín, I., López Escobar, A., Fernández Villalba, E., Romero Blanco, I. and Touza Pol, P., 2010. Randomized controlled trial of early skin-to-skin contact: effects on the mother and the newborn. *Acta Paediatrica*, 99(11), pp.1630-1634.
- McFerrin, T.A., 2008. *Oxford Dictionary of Nursing*. 4th Edition. United Kingdom. Oxford University Press.

- Moon, R.Y; American Academy of Pediatrics, Task Force on Sudden Infant Death Syndrome. Policy statement: SIDS and Other sleep-related Infant deaths: Expansion of Recommendations for a Safe Infant Sleeping Environment. *Pediatrics* 2011;128:1030-1039.
- Moore, K. 2018. *Mowbray Maternity Hospital Presentation*. June 2018, Cape Town. [Unpublished].
- McQuoid-Mason, D.J. and Dada, M.A., 2011. *AZ of nursing law*. Juta and Company Ltd.
- O'Brien, K., Bracht, M., Macdonell, K., McBride, T., Robson, K., O'Leary, L., Christie, K., Galarza, M., Dicky, T., Levin, A. and Lee, S.K., 2013. A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. *BMC Pregnancy and Childbirth*, 13(1), p.S12.
- Premji, S.S., Young, M., Rogers, C. and Reilly, S., 2012. Transitions in the early-life of late preterm infants: vulnerabilities and implications for postpartum care. *The Journal of perinatal & neonatal nursing*, 26(1), pp.57-68.
- Purdy, I.B., Craig, J.W. & Zeanah, P. 2015. NICU discharge planning and beyond: recommendations for parent psychosocial support. *Journal of Perinatology*, 35 (Suppl 1), p. S24.
- Reid, A.E., Hendricks, M.K., Groenewald, P. & Bradshaw, D., 2016. Where do children die and what are the causes? Under-5 deaths in the Metro West geographical service area of the Western Cape, South Africa, 2011. *South African Medical Journal*, 106(4), pp.359-364.
- Polit, D.F. and Beck, C.T., 2010. *Essentials of nursing research: Appraising evidence for nursing practice*. Lippincott Williams & Wilkins.
- Republic of South Africa. 2015. *Guidelines for Maternity Care in South Africa. A manual for clinics, community health centres and district hospitals*. 4th Ed. Department of Health. Pretoria: Government Printers.
- Rule, P. & John, V. 2011. *Your guide to Case Study Research*. 1st Edition, Pretoria: Van Schaik Publishers.
- Statistics South Africa, 2015. *Millennium Development Goals 4: Reduce child mortality 2015/Statistic South Africa*, Pretoria: Statistics South Africa, 2015
- Smith, V.C., Hwang, S.S., Dukhovny, D., Young, S. & Pursley, D.M. 2013. Neonatal intensive care unit discharge preparation, family readiness and infant outcomes: connecting the dots. *Journal of Perinatology*, 33(6), p.415. doi:10.1038/jp.2013.23.

Report (E/2016/75): The Sustainable Development Goals Reports. 2017. Inter-Agency Meeting on Preparation for the 2017 SDG Reports. 1-2 March 2017. New York. 2016.

Van Niekerk, A. Neonatologist, 2018. *Personal interview*. May 2018, Cape Town. [Unpublished].

WCDoH, 2011. 2020 *The future of health care in the westerncape*2011/11. Western Cape Department of Health, Cape Town, South Africa. Available: https://www.westerncape.gov.za/other/2011/12/healthcare_2020_-_december_2020.pdf [2017, September 1].

Western Cape Government: Department of Health, 2011. Kangaroo Mother Care Policy and Guideline. Cape Town: Western Cape Government.

Western Cape Government: Department of Health (WCDoH). 2017. *Transformation Strategy*. Cape Town: Western Cape Government.

WCDoH, 2016. First 1000 days Research Newsletter. In Matthews, S., Martin, L.J., Coetzee, D. & Scott, C. 2016. *Deaths from injuries in children under 18 years of age in Metro West, Cape Town: Data from the Child Death Review 2014 and 2015*. Western Cape Department of Health, Cape Town, South Africa.

World Medical Association Declaration of Helsinki. 2008. *Ethical Principles for Medical Research Involving Human Subjects*. 59th WMA General Assembly. Seoul: Korea.

World Health Organization (WHO): 2012. *Preterm birth. (Fact sheet)*, Review November 2016, 363 [Online]. Available: <http://www.who.int/mediacentre/factsheets/fs363/en/> [Accessed 2017, May 19].

World Health Organization (WHO): 2017. *The cost of a polluted environment: 1.7 million child deaths a year, say WHO*. [Online]. Available: <http://www.who.int/mediacentre/news/releases/2017/pollution-child-death/en/> [Accessed 2017 May 19]

Yin, R.K. 2014. *Case Study Research, Design and Methods*. 5th Edition, California, SAGE Publishers.

Appendix 1: ethical approval from Stellenbosch University

Approved with Stipulations

New Application

09/05/2018

Project ID: 6317

HREC Reference #: S18/02/030

Title: Perspectives of preterm infant caregivers on basic life support skills training before discharge: A descriptive case study at a Secondary Hospital in Western Cape, South Africa

Dear Miss Anne Africa,

The **Response to Modifications** received on 16/04/2018 20:08 was reviewed by members of the **Health Research Ethics Committee 2 (HREC2)** via Minimal Risk Review procedures on 09/05/2018 and was approved with one stipulation.

Please note the following information about your approved research protocol:

Protocol Approval Period: **09-May-2018 – 08-May 2019.**

The stipulation of your ethics approval is as follows:

1. Please indicate compensation for participants for time and inconvenience.

Please remember to use your **Project ID [6317]** and ethics reference number on any documents or correspondence with the HREC concerning your research protocol.

Translation of the consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note that this decision will be ratified at the next HREC full committee meeting. HREC reserves the right to suspend approval and to request changes or clarifications from applicants. The coordinator will notify the applicant (and if applicable, the supervisor) of the changes or suspension within 1 day of receiving the notice of suspension from HREC. HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note you can submit your progress report through the online ethics application process, available at: <https://apply.ethics.sun.ac.za> and the application should be submitted to the Committee before the year has expired. Please see [Forms and Instructions](#) on our HREC website for guidance on how to submit a progress report.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics)

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Francis Masiye,

HREC Coordinator,

Appendix 2: permission obtained from institutions / Department of Health



RE: APPLICATION TO CONDUCT RESEARCH AT MMH

 You forwarded this message on 2018/07/23 15:20.



RE WC_201805_034 (118 KB)
Outlook item

Good afternoon Beatrice,

Permission for this research was already conducted on 26 June 2018.

However, my inbox has been very full, and hence the response may not have reached you. My apologies.

Kind regards,

Janine

Janine Joemat

Chief Executive Officer: Mowbray Maternity Hospital

General Specialist Hospitals

Department of Health

Western Cape Government

Private Bag x7 Mowbray 7705;

12 Hornsey Road, Mowbray 7700



Health impact assessment
Health research sub-directorate
Health.Research@westerncape.gov.za
Tel: +27 21 483 0866; fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: WC_201805_034
ENQUIRIES: Dr Sabela Petros

Stellenbosch University
Tygerberg Hospital
Francie Van Zijl Drive
Parow Valley
Cape Town
7305

For attention: Ms Anne Africa, Dr Doreen M'Rthaa

Re: Perspectives of preterm infant caregivers on basic infant life support skills training before discharge: A descriptive case study at a Secondary hospital in Western Cape, South Africa.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following person to assist you with any further enquiries in accessing the following sites:

Mowbray Maternity Hospital

Dr Janine Joemat

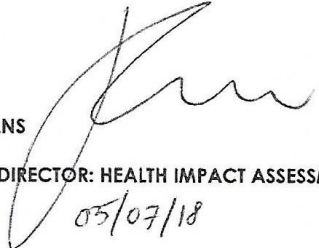
021 659 5544

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. By being granted access to provincial health facilities, you are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of your project. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the *estimated completion* date which was submitted, you are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely


DR J EVANS
ACTING DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 05/07/18

**Appendix 3: Parents Of Preterm Infants Who Received The BILS Skills Training Before
Discharge Consent: English**



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

TITLE OF RESEARCH PROJECT:

PERSPECTIVES OF CAREGIVERS OF PRETERM INANTS ABOUT BASIC INFANT LIFE SUPPORT SKILLS TRAINING BEFORE DISCHARGE:

A DESRIPTIVE SINGLE CASE STUDY AT A SECONDARY HOSPITAL, IN CAPE TOWN METROPOLE, SOUTH AFRICA

**STELLENBOSCH UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH**

You are being invited to participate in the research study conducted by Anne Beatrice Africa and Doreen M'Rithaa from the Midwifery Department at Stellenbosch University. You were asked to be a participant because you received the basic infant life support skills training before your infant was discharged.

PURPOSE OF THE STUDY

The aim of this study is to find out your perspectives as parents/caregivers of preterm infants about the basic infant life support skills training programme you received before your infant was discharged home.

WHAT WILL BE EXPECTED OF YOU?

Once you have decided to voluntary make an informed decision to take part in the study you will be asked to sign the informed consent form which will be done within a few minutes. Thereafter the researcher will interview you or have a conversation with you to get your perspectives/views about the basic infant life skills support training, also known as CPR training you received before your infant was discharged home. The interview or conversation will be done in a private room near the high-risk clinic which will last up to an hour or longer if needed.

The interview will be audio recorded while you are sharing your perspectives or perspectives about the basic infant life support skills training with your permission.

POSSIBLE RISKS OR DISCOMFORTS

There might be risks that you might feel emotional while you are sharing your views on the basic life support skills training you received but be assured we will refer you to another professional if you need counselling.

WHAT ARE THE BENEFITS OF THIS STUDY?

This study might not be to your benefit as you had the training already but it will assist us to find out information that will help health care professionals to equip parents/caregivers of preterm infants with basic infant life support skills, before discharge to save their infants' lives after discharge.

WILL YOU RECEIVE ANY PAYMENT FOR TAKING PART IN THE RESEARCH?

No, you will not receive any money to take part in this study.

PRIVACY AND CONFIDENTIALITY

The researcher will keep the recorded information confidential and it will only be available to the research team which is I and my supervisor. Your name will not be mentioned in the research project report to ensure your privacy.

WHAT ARE YOUR RIGHTS ABOUT PARTICIPATION AND WITHDRAWAL?

Please note that you can choose to be part of this research. Your participation is totally voluntary. You may refuse to take part in the research at any stage. If the interview has already taken place, and you change your mind to take part in the research then you may ask the researcher that the information given by you be removed from the research study without any consequences. The researcher will not mention your name in the research report that will be shared with other health care professionals and academics.

CONTACT DETAILS OF THE RESEARCHERS'

Permission was granted by the Health Research Ethics Committee of Stellenbosch University and the Western Cape Provincial Department of Health to conduct this research. If you have any questions or concerns about the study

Please contact the researcher Anne Beatrice Africa at [beatriceafrica@vodamail.co.za; 0724457885] or my supervisor, Dr Doreen M'Rithaa at [dkm@sun.ac.za; 07 886 4448] if you have any questions.

WHAT IS YOUR RIGHTS AS A PARTICIPANT?

You have the right to refuse to participate in the research or withdraw from the study at any time, without any explanations and with no consequences. If you have any questions about your rights as a research participant, please contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division of Research Development].

DECLARATION OF CONSENT BY THE PARTICIPANT

As the participant I agree that:

- I have read the above information and it is written in a language that I understand.
- I was given an opportunity to ask questions and all my questions have been answered.
- All concerns about privacy, and confidentiality as well as the use of the information I provide, have been explained.

By signing below, I _____ agree to voluntary take part in this research study, conducted by Anne Beatrice Africa.

Signature of Participant

Date

DECLARATION BY THE PRINCIPAL INVESTIGATOR
--

As the **principal investigator**, I wish to declare that the information within this document has been thoroughly explained to the participant. I also declare that the participant has been given an opportunity to ask any questions. In addition, I would like to select the following option:

	The discussion with the participant was done in a language in which the participant is fluent.
	The discussion with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this “Consent Form” is available to the participant in a language in which the participant is fluent.
	<div style="display: flex; justify-content: space-between;"> </div> <div style="display: flex; justify-content: space-between;"> Signature of Principal Investigator Date </div>

Appendix 4: Doctors' Consent: English



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

TITLE OF RESEARCH PROJECT:

PERSPECTIVES OF CAREGIVERS OF PRETERM INFANTS ABOUT BASIC INFANT LIFE-SUPPORT SKILLS TRAINING BEFORE DISCHARGE:

A DESCRIPTIVE SINGLE CASE STUDY AT A SECONDARY HOSPITAL, IN CAPE TOWN METROPOLE, SOUTH AFRICA

STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

You are invited to participate in the research study conducted by Anne Beatrice Africa and Doreen M'Rithaa from the Midwifery Department at Stellenbosch University. As doctors you are invited to participate in the research, because you were involved in the compilation of the basic infant life-support skills training standard operational plan or because you are involved in the discharge planning of preterm infants.

PURPOSE OF THE STUDY

The purpose of this study is to explore your perspectives as caregivers/healthcare professionals about the basic infant life-support skills training to caregivers of preterm infants before discharge.

WHAT WILL BE EXPECTED OF YOU?

Once you have decided to voluntarily take part in the study you will be asked to sign the informed consent form. Thereafter, you will be individually interviewed by the researcher at a time most suitable to you. The individual interview will be taking place in an office or private room to get your perspectives about the basic infant life-skills support training that is provided to caregivers of preterm infants before discharge. The in-depth interview will be done in a private room at the hospital which will last up to an hour or longer if needed.

The interview will be audio recorded with your permission, while you are sharing your perspectives about the basic infant life support skills training.

POSSIBLE RISKS OR DISCOMFORTS

There might be minimal risks and you could feel emotional, while you are sharing your views on the basic life-support skills training you are involved in but professional counselling services will be available if you need counselling.

WHAT ARE THE BENEFITS OF THIS STUDY?

This study might benefit you as healthcare professionals to enhance the basic infant life-support skills training programme at the secondary public hospital and other healthcare facilities. The study might also obtain evidence that will assist health-care professionals to equip caregivers of preterm infants with basic infant life-support skills, before discharge to save their infants' lives after discharge.

WILL YOU RECEIVE ANY PAYMENT FOR TAKING PART IN THE RESEARCH?

No, you will not receive any money for your time and any inconvenience caused to take part in this study.

PRIVACY AND CONFIDENTIALITY

The researcher will keep the recorded information confidential and it will only be available to the research team which is my supervisor and I. Your name will not be mentioned in the research project report to ensure your privacy/ anonymity.

WHAT ARE YOUR RIGHTS ABOUT PARTICIPATION AND WITHDRAWAL?

Please note that you can choose to be part of this research. Your participation is totally voluntary. You may refuse to take part in the research at any stage. If the interview has already taken place, and if you change your mind about continuing to take part in the research, then you may ask the researcher that the information given by you, be removed from the research study without any consequences. The researcher will not mention your name in the research report that will be shared with other healthcare professionals and academics.

CONTACT DETAILS OF THE RESEARCHERS

Permission was granted by the Health Research Ethics Committee of Stellenbosch University and the Western Cape Provincial Department of Health to conduct this research. If you have any questions or concerns about the study

Please contact the researcher Anne Beatrice Africa, [beatriceafrica@vodamail.co.za; 0724457885] or my supervisor, Dr Doreen M'Rithaa [dkm@sun.ac.za; 07 886 4448].

WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

You have the right to refuse to participate in the research or withdraw from the study at any time, without any explanations and with no consequences. If you have any questions about your rights as a research participant, please contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division of Research Development.

DECLARATION OF CONSENT BY THE PARTICIPANT

As the participant I agree that:

- I have read the above information and it is written in a language that I understand.
- I was given an opportunity to ask questions and all my questions have been answered.
- All concerns about privacy, and confidentiality, as well as the use of the information I provide, have been explained.

By signing below, I _____ agree to voluntary take part in this research study, conducted by Anne Beatrice Africa.

Signature of Participant

Date

As the participant I agree that:

- I have read the above information and it is written in a language that I understand.
- I was given an opportunity to ask questions and all my questions have been answered.
- All concerns about privacy, and confidentiality, as well as the use of the information I provide, have been explained.

By signing below, I _____ agree to voluntary take part in this research study, conducted by Anne Beatrice Africa.

Signature of Participant

Date

DECLARATION BY THE PRINCIPAL INVESTIGATOR

As the **principal investigator**, I wish to declare that the information within this document has been thoroughly explained to the participant. I also declare that the participant has been given an opportunity to ask any questions. In addition, I would like to select the following option:

	The discussion with the participant was done in a language in which the participant is fluent.
	The discussion with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this "Consent Form" is available to the participant in a language in which the participant is fluent.

	Signature of Principal Investigator Date

Appendix 5: Midwives' Consent: English



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvenoot • your knowledge partner

TITLE OF RESEARCH PROJECT:

PERSPECTIVES OF CAREGIVERS OF PRETERM INFANTS ABOUT BASIC INFANT LIFE-SUPPORT SKILLS TRAINING BEFORE DISCHARGE:

A DESCRIPTIVE SINGLE CASE STUDY AT A SECONDARY HOSPITAL, IN CAPE TOWN METROPOLE, SOUTH AFRICA

STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

You are being invited to participate in the research study conducted by Anne Beatrice Africa and Doreen M'Rithaa from the Midwifery Department at Stellenbosch University. As midwives you are invited to participate in the research because you were involved in the pre-discharge planning or you provided the basic infant life-support skills training to caregivers/parents of preterm infants.

PURPOSE OF THE STUDY

The purpose of this study is to explore your perspectives as caregivers/healthcare professionals about the basic infant life support skills training to caregivers of preterm infants before discharge.

WHAT WILL BE EXPECTED OF YOU?

Once you have decided to voluntarily take part in the study, you will be asked to sign the informed consent form. Arrangements will be made with you to determine the most suitable time for you to participate in one group discussion with three to six registered midwives. The group discussion will last for one hour or longer if needed in a private room to get your perspectives or perspectives about the basic infant life- support skills training to caregivers of preterm infants before discharge.

The group discussion will be audio recorded with your permission, while you are sharing your perspectives about the basic infant life-support skills training.

POSSIBLE RISKS OR DISCOMFORTS

There might be minimal risks that you could feel emotional while you are sharing your views on the basic life-support skills training you are involved in, but professional counselling services will be available if you need counselling.

WHAT ARE THE BENEFITS OF THIS STUDY?

This study might benefit you as healthcare professionals to enhance the basic infant life-support skills training programme at the secondary public hospital and other healthcare facilities. The study might also obtain evidence that will assist health-care professionals to equip caregivers of preterm infants with basic infant life-support skills, before discharge to save their infants' lives after discharge.

WILL YOU RECEIVE ANY PAYMENT FOR TAKING PART IN THE RESEARCH?

No, you will not receive any money for your time or any inconvenience caused to take part in this study.

PRIVACY AND CONFIDENTIALITY

The researcher will keep the recorded information confidential and it will only be available to the research team which is my supervisor and I. Your name will not be mentioned in the research project report to ensure your privacy/ anonymity.

WHAT ARE YOUR RIGHTS ABOUT PARTICIPATION AND WITHDRAWAL?

Please note that you can choose to be part of this research. Your participation is totally voluntary. You may refuse to take part in the research at any stage. If the interview has already taken place and if you change your mind about continuing to take part in the research, then you may ask the researcher that the information given by you, be removed from the research study without any consequences. The researcher will not mention your name in the research report that will be shared with other healthcare professionals and academics.

CONTACT DETAILS OF THE RESEARCHERS

Permission was granted by the Health Research Ethics Committee of Stellenbosch University and the Western Cape Provincial Department of Health to conduct this research. If you have any questions or concerns about the study

Please contact the researcher Anne Beatrice Africa, [beatriceafrica@vodamail.co.za; 0724457885] or my supervisor, Dr Doreen M'Rithaa, [dkm@sun.ac.za; 07 886 4448].

WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

You have the right to refuse to participate in the research or withdraw from the study at any time, without any explanations and with no consequences. If you have any questions about your rights as a research participant, please contact Ms Maléne Fouché. [mfouche@sun.ac.za; 021 808 4622] at the Division of Research Development.

DECLARATION OF CONSENT BY THE PARTICIPANT

As the participant I agree that:

- I have read the above information and it is written in a language that I understand.
- I was given an opportunity to ask questions and all my questions have been answered.
- All concerns about privacy, and confidentiality, as well as the use of the information I provide, have been explained.

By signing below, I _____ agree to voluntary take part in this research study, conducted by Anne Beatrice Africa.

Signature of Participant **Date**

DECLARATION BY THE PRINCIPAL INVESTIGATOR

As the **principal investigator**, I wish to declare that the information within this document has been thoroughly explained to the participant. I also declare that the participant has been given an opportunity to ask any questions. In addition, I would like to select the following option:

	The discussion with the participant was done in a language in which the participant is fluent.
	The discussion with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this “Consent Form” is available to the participant in a language in which the participant is fluent. Signature of Principal Investigator Date

Appendix 6: Interview Guide Parents

<i>Appendix 1: SEMI-STRUCTURED INDIVIDUAL INTERVIEWS WITH CAREGIVERS/PARENTS</i>			
CAREGIVERS			
Mother	Grand mother	Aunt	Father/Guardian
PREFERRED LANGUAGE	English	Afrikaans	Xhosa/other
1. Tell me more about yourself			
2. Let us talk about the BILS/CPR training that you attended before your infant/baby went home?			
Probes: Tell me more <ul style="list-style-type: none"> • How was the training provided? • How were you able to understand it? • How was the information clear? • How was the demonstration doable? • How did you identify danger signs? • How do you remember steps of (BILS) skills? 			
3. Let's talk about how you used this information since your infant/baby was discharged home?			
Probes: <ul style="list-style-type: none"> • What was wrong with baby? • What did you do? • How did it help? 			
4. Let us talk more about the discharge information that was given to you before your baby was discharged.			
5. What do you suggest the hospital staff members do differently to improve the (BILS) skills training to caregivers/parents of preterm infants, before discharge?			

Appendix 7: Interview Guide Midwives focus group

SEMI-STRUCTURED FOCUS GROUP INTERVIEWS WITH THE MIDWIVES			
FOCUS GROUPS INTERVIEWS 3 – 4 MIDWIVES PER GROUP			
MIDWIVES	Assistant Manager /Operational Manager	Advanced Midwife	Basic Midwife
1. Tell me more about yourself.			
Probes: discharge planning, requesting training for caregivers, compilation of guidelines			
2. Let's talk about the rationale for the implementation of the (BILS) skills training to caregivers of the preterm infants at this hospital?			
3. Let us talk about feedback you received regarding the (BILS) skills training from other colleagues or caregivers that you would like to share?			
Probes: positive feedback, negative feedback, workload, resources			
4. Let's talk about the (BILS) skills training from offered to caregivers of preterm infants at this hospital.			
Probes: Feedback received			
Positive feedback, negative feedback, workload, resources			
5. Let's talk about your recommendations for future training.			
<ul style="list-style-type: none"> • Challenges • Enhancers 			

Appendix 3: Interview Guide individual interviews with Doctors

SEMI-STRUCTURED INDIVIDUAL INTERVIEWS WITH DOCTORS			
DOCTORS	Head Department	of Consultants	Medical Officers, other
SEMI-STRUCTURED INDIVIDUAL INTERVIEWS			
1. Tell me more about yourself.			
2. Let us talk about your involvement in the (BILS) skills training to caregivers of preterm infants, before discharge.			
Probes: discharge planning, requesting training for caregivers, compilation of guidelines			
3. Let's talk about the rationale for the implementation of the (BILS) skills training to caregivers of the preterm infants was this hospital?			
4. Let's talk about the (BILS) skills training offered to caregivers of preterm infants at this hospital?			
Probes: Feedback received			
<ul style="list-style-type: none"> • Probes: positive feedback, negative feedback, workload, resources 			
5. Let's talk about your recommendations for future training.			
<ul style="list-style-type: none"> • Challenges • Enhancers 			

Appendix 8: Confidentiality agreement with data transcriber (if applicable) / permission for use
of an instrument

TRANSCRIBER CONFIDENTIALITY
AGREEMENT

I, the undersigned Leigh Story

1. herewith undertake that all information disclosed or submitted, either orally, in writing or in other tangible or intangible form by Anne Beatrice Africa to me, or made available to me, or details of Anne Beatrice Africa' business or interest of which I may become aware of in respect of transcriptions being done by myself for Anne Beatrice Africa, to keep confidential and not to divulge to anyone for which Anne Beatrice Africa did not give written consent;
2. guarantee that I will apply the information, detail or knowledge in **clause 1** only for the purpose of the intended research;
3. Indemnify Anne Beatrice Africa against any claims that may be instituted against Anne Beatrice Africa, amounts that may be claimed or losses that Anne Beatrice Africa may suffer in consequence of a violation by me of any provision included in this agreement.

SIGNED at Cape Town on 23rd July 2018



A handwritten signature in black ink, appearing to read 'Leigh Story', is positioned above a solid horizontal line. The signature is written in a cursive style with a large loop at the end.

Appendix 9: Extract of transcribed focus group discussion: midwives 2**Speaker Key:**

IV Interviewer

FI Female Interviewee

IV Anyway ladies, so remember, I asked you to share your perspectives about the basic infant life support training. Tell me more about your specific involvement with the basic life support training.

[00:11:16]

FI For me, it's not a constant thing. It's just often on weekends the consultants will say oh, can you just go and show a mom or two how to do basic resuscitation. I actually enjoy it, because it's something that you can teach someone who will never forget it, hopefully. I try not to create a very stiff environment, I try and make it fun so that, because it is a serious matter, and often if you create it in a fun environment, they're going to remember it quicker and easier than if you do it in a very like stiff environment.

So, I do it over weekends, or perhaps after hours, if needed, if it hasn't been done, but it's not only to premature babies. I tend to also do it to the sicker term babies, so that the moms are quite comfortable. I think it has, hopefully it has long benefits. I often get all the moms to interact. So, I don't just do it one on one.

Even if Sister has done it already, I find it quite fun, because then I try and look through the files quietly before I start, and then I kind of like say okay, maybe Mommy, can you perhaps tell us what we should do? Then that kind of tells you okay, was she listening or wasn't she listening, and then just build on that. I tend to ask questions afterwards, like maybe if there are any questions, can they tell me exactly what I showed them.

I have also gone to the wards previously, B Ward, to do resus training for certain moms there, and that was also nice, because I remember once there was a CSP who wanted to I know what I was doing. So, I showed her what I was doing, and the importance of sharing our own knowledge with the public.

[00:13:35]

IV So tell me more about the postnatal ward, the mothers that you would you would normally go to.

FI The postnatal wards are normally moms that have perhaps premature babies, but perhaps they haven't gone or needed to come to the nursery. It's sometimes moms who have had still births, or who have had sudden infant death syndrome at home, and it's often picked up by the medical officers that maybe this mom is very anxious, or there is a history of neonatal death or something like that.

Then those are the moms who are very anxious, who they ask me to do. Often it's hard, because it's not in English. I mean, the mom isn't fluent in English, so that is

rather interesting sometimes for me, because maybe the mom is Xhosa or a foreigner, but we get through it, and we interact well. With those moms, those are the ones I do one on one. I would maybe involve a student nurse or somebody who wants to see how it's done, and when I leave, I take my time. I don't just say this and this and this is going to do.

[00:14:48]

I try and stay with the patient for about ten minutes, so that she can actually show me what I have just shown her as well. Then I give her a leaflet, which I bring down anyway from KMC, of what to do, and I tell her to please put it inside the road to health booklet, or put it on their fridge, something like that. So, they go home with information. I often ask a Sister, if the child is being discharged, to make sure the mom takes the page home with her.

IV You mentioned that sometimes because you are giving it in English, there are mothers that are maybe not speaking English fluently, but then you mentioned a leaflet. So, would that leaflet also be, tell me more about the leaflet.

FI The leaflet is just designed so that moms can remember the steps. It's mainly in English.

FI2 No, there are five different languages.

FI Oh well, that's awesome. I did not know that [laughs]. Okay, so now I know that. It's good for them if they get it in their own language, because then they can read it and understand it as well, which is perfectly fine. I just didn't realise that. So, if that's the case, I would still do it in English, and then give it to them in whatever language they have. It's good, because it's on paper and they can remember, and they can put it in a safe place for future use.

IV Thank you for that in-depth information that you gave to us, thanks so much. Who would like to share next?

FI2 I haven't got much to add to what O said. She has really gone into detail.

IV But from your perspective.

FI2 My challenge is, often the Xhosa mothers don't seem to understand what I am saying, even though the pamphlet is there. But I have noticed that if I try and do resus training and we go over it and then I ask questions, they will be the ones to answer and reiterate on that. The challenge is actually time. You know, you can't rush this in ten minutes, and there isn't always three quarters of an hour, because you really, as O says, I tend to start off asking them a little bit about how they felt when they had a premature baby, because they do want to share all that.

[00:17:29]

That loosens things up, and then we go into the training. As O says, we also joke a lot, and try not to make it too serious. I always say there is a very small chance it will happen to your baby, so that they are not scared out of their wits.

Appendix 10: Declarations by Language and Technical Editors

Editing Service: Lee Kemp

14 Carlisle St

Mount Croix

Port Elizabeth

6001

29 NOVEMBER 2018

082 723 5408

TO WHOM IT MAY CONCERN

EDITING OF TREATISE: Ms Beatrice Africa

This serves to confirm that I edited Ms Africa's Masters' in Nursing treatise.

The editing covered all aspects of language, punctuation and layout. I also crosschecked in-text referencing against the reference list.

Yours faithfully



Ms L. Kemp

B. A. (Hons English); MBA