DECISION-MAKING IN THE NEONATAL INTENSIVE CARE:

PRE-DISCHARGE AND POST-DISCHARGE

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TABLE OF CONTENTS

FOREWORD		8
TWO CONTRIBUTIONS FROM PARENTS WHO HAD PREMATURE BABIES		1
SECTION A: LEGAL AND ETHICAL ISSUES IN NEONATAL INTENSIVE CARE		
CHAPTER 1 (BIOMEDICAL ETHICS)		
1.1	Ethical issues in neonatal care	17
1.1.1	Introduction	17
1.1.2	Ethical theories	18
1.1.2.1	*Deontololgy*	18
1.1.2.2	*Utilitarianism*	19
1.1.2.3	*Virtue ethics*	19
1.1.3	Principles of biomedical ethics	20
1.1.3.1	*Autonomy*	20
1.1.3.2	*Non-maleficence*	22
1.1.3.3	*Beneficence*	23
1.1.3.4	*Justice*	25
1.1.4	Quality of life versus sanctity of life	26
1.1.5	Conclusion	29
CHAPTER 2 (INTERNATIONAL LAW AND THE CONSTITUTION)		
2.1	Introduction	31
2.2	International Human Rights Instruments	31
2.3	Millennium Development Goals	34
2.4	The Constitution of the Republic of South Africa, 1996	35
2.4.1	The right to life	35
2.4.2	The right to dignity	38
2.4.3	The rigt of access to health care	38
2.4.4	The right to emergency medical care	39
2.4.5	The best interests of the child	40
CHAPTER 3 (SOUTH AFRICAN LEGISLATION)		
3.1	The National Health Act 61 of 2003	43
3.2	The Children’s Act 38 of 2005	44
3.2.1	Consent to medical treatment	44

3.2.2 Children with disabilities and chronic illnesses: Section 11 of the Children's Act 46
CHAPTER 4 (WHEN THERE ARE DISPUTES IN THE NICU: LITIGATION OR MEDIATION?)
4.1 Introduction 47
4.2 Mediation 47
4.2.1 Legislative foundation for mediation in South Africa 49
4.2.2 The mediation process 50
4.3 Litigation 51
CHAPTER 5 (GUIDELINES FOR CRITICAL CARE DECISIONS: PRE-DISCHARGE)
5.1 Introduction 55
5.2 Care at the limits of viability 55
5.3 The "Gray Zone" 57
5.4 Ethical decision making 59
5.5 Selective non-treatment in newborns 60
5.5.1 Definitions 60
5.6 Management after end-of-life decisions 61
CHAPTER 6 (MEDICATION ERRORS IN A NEONATAL INTENSIVE CARE UNIT)
6.1 Introduction 64
6.2 Risk factors associated with medication errors in a neonatal intensive care unit (NICU) 65
6.3 Classification of medication errors 66
6.4 Causes of medication errors 68
6.5 The role of the clinical pharmacist in medication errors 69
6.6 The role of the clinical pharmacist in a neonatal intensive care unit 71
CHAPTER 7 (SUPPORT AFTER HOSPITAL DISCHARGE)
7.1 Introduction 73
7.2 Preparing for discharge 73
7.3 Bonding and attachment 76
7.4 Parental support needs in the community 79
7.5 Specific situations after discharge 83
7.5.1 Weight and feeding of the infant discharged from NICU 84
7.5.2 Oxygen dependant infants discharge from NICU 84

7.5.3 Infant discharged from NICU requiring nasogastric feeds 85
7.5.4 Infant discharged from NICU with a tracheostomy 86
7.6 Availability of resources 87
7.7 Conclusion 88
CHAPTER 8 (GUIDELINES FOR FEEDING CRITICALLY ILL CHILDREN IN THE PAEDIATRIC INTENSIVE CARE UNIT AND THE NEONATAL INTENSIVE CARE UNIT)
8.1 Feeding of the critically ill child in NICU 89
8.2 Assessment of nutritional status 90
8.2.1 Anthropometry 90
8.2.2 Clinical assessment 90
8.2.3 Biochemistry 90
8.2.4 Blood gases 91
8.3 Nutrional requirements 91
8.3.1 Energy 91
8.3.2 Protein 92
8.3.3 Carbohydrate 92
8.3.4 Fat 93
8.3.5 Fluid 93
8.3.6 Route of feeding 93
8.3.6.1 Enteral feeding 94
8.3.6.2 Contra-indications for enteral feeding 96
8.3.6.3 Route and tube placement for enteral feeding 96
8.3.6.4 Method of infusion 97
8.3.6.5 Feeding selection 97
8.3.6.6 Enteral feed hanging time 98
8.3.6.7 Monitoring of enteral feeding 98
8.4 Feeding of premature and low birth weight infants in the neonatal intensive care unit 101
8.4.1 Nutrition 102
8.4.2 Parenteral nutrition (PN) 102
8.4.3 Enteral nutrition 103
8.4.3.1 Fluid requirements 103
8.4.3.2 Energy 103

8.4.3.3. Protein 104
8.4.3.4 Fat 104
8.4.3.5 Carbohydrate 104
8.4.3.6 Type of feed 105
8.4.3.7 Micro-nutrient supplementation 106
8.5 Monitoring of nutritional status 107
8.5.1 Anthropometry and growth charts 107
8.5.2 Biochemistry 107
8.6 Kangaroo Mother Care 108
8.7 Discharge and follow-up 109
CHAPTER 9 (ETHICAL GUIDELINES IN NEONATAL CARE: AUDIOLOGY)
9.1 Nature of speech-language therapy services in neonatal intensive care 111
9.2 Prevalence and outcomes of hearing loss in neonates 111
9.3 Rights of infants and families 113
9.4 Roles and responsibilities 114
9.4.1 Departments and agencies 114
9.4.2 Professionals 114
9.4.3 Principles 115
9.4.4 Guidelines 116
CHAPTER 10 (ETHICS IN NEONATAL CARE: SPEECH-LANGUAGE PATHOLOGY)
10.1 Nature of speech-language therapy services in neonatal intensive care 119
10.2 Prevalence of communication disorders in preterm and low birth weight infants 119
10.3 Risk indicators for communication disorders (Rosetti, 2001) 120
10.4 NICU Interventions by speech-language therapists 120
CHAPTER 11 (CRITICAL CARE GUIDELINES FOR NEONATES IN SOU
11.1 Introduction 123
11.2 Occupational therapy approaches within the NICU 123
11.3 Occupational therapy interventions concerning the neonate 124
11.4 Splinting in the NICU 125
11.5 Developmental interventions 127

115.1 External sensory stimuli 129
11.5.1.1Vestibular input 129
11.5.1.2Olfactory and gustatory input 129
11.5.1.3Auditory input 130
11.5.1.4Visual input 131
11.5.1.5Positioning and handling 132
11.6 Joint attention interventions 155
11.7 Post discharge occupational therapy intervention 160
11.8 Conclusion 164
CHAPTER 12 (CRITICAL CARE GUIDELINES: A PSYCHOLOGICAL PERSPECTIVE)
12.1 Introduction 166
12.2 Ethical issues regarding decision making and psychological support 168
12.3 Psychological support of the various role players within presenting situation and with the decision-making process 169
12.3.1 Parents and primary caregivers 169
12.3.2 Nature of psychological support that should be given to parents and primary caregivers 170
12.3.3 Framework of psychological support given to parents and primary caregivers during the NICU admission and stay 172
12.3.4 Psycho-educational information provided to all parties during the coping stage in order to assist with decision making 176
12.3.4.1Initial interventions 176
12.3.5 Healthcare professionals 181
12.3.6 Healthcare administrators within the hospital context 181
12.3.7 Conclusions and recommendations 181
ABBREVIATIONS 182
BIBLIOGRAPHY 185

FOREWORD

Modern medicine has made it possible for more and more premature and critically ill neonates to survive. Athough more survive and thrive, there are also more who survive with severe disabilities. As a result of this physicians and parents are increasingly faced with difficult decisions regarding the treatment of these neonates, not only at birth, but also while the neonate is still being hospitalised. However, it does not all end when the baby is discharged from hospital, it is also important that the correct treatment is continued when the baby goes home. For this reason, not only guidelines are provided that should be followed during the baby's hospital stay, but also guidelines pertaining to the different therapeutic interventions are included in this document. The document concludes with guidelines for psychological support which is essential whether the baby survives or not.

The main aim of this report is to assist the health care team and the parents in this decision-making process. The task team acknowledges that these decisions are very emotional decisions and we hope that this report will assist all the role players in the decision making process.

Critical care decisions cannot be made without also considering the legal and ethical issues pertaining to children in general and neonates in particular. It is hoped that this report will also shed some light on these issues for members of the medical profession.

This report is to a great extent based on the findings of the team leader's doctoral thesis.[1] This research revealed that in South Africa there are to date no guidelines specifically drafted for critical care decisions, similar to guidelines in other parts of the world, such as those published by the Royal College of Paediatrics and the Nuffield Council on Bioethics in the United Kingdom. The only document that is available, is a document published by the Health Professions Council of South

[1] Van der Westhuizen CS *A Proposed Framework for the Legal Protection of Premature and Critically-ill Neonates in the Context of South African Child Law* (unpublished doctoral thesis, UFS,) (2012).

Africa, entitled “Guidelines for the withholding and withdrawing of treatment”.[2] This document provides general guidelines concerning withholding or withdrawing of treatment and is not specifically aimed at the neonatal intensive care, although certain aspects covered in this document are also relevant to the treatment of neonates.

South Africa has a unique health care system, on the one hand there are private hospitals and private health care and on the other hand there are public hospitals and public health care. The public health care renders services to the greater part of the population, while the private health care service renders services to those who belong to medical aid funds and those with enough resources to pay for medical services themselves.[3] The fact that at the moment there are no guidelines for critical care decisions available has the effect that the same approach is not necessarily followed by health care teams in hospitals private as well as public. This creates inconsistency in borderline cases such as very low birth weight, low gestational age and congenital abnormalities. This reports hopes to address these inconsistencies.

This document is a project of the Biotechnology and Medical Law Law Flagship in the College of Law, UNISA. The guidelines were drafted by a multidisciplinary task team consisting of members who are specialists in their field. I would like to thank every member (as well as those who are not members of the task team and made contributions) for their enthusiasm and their contributions. As the team leader, I have a legal background and not a medical background. Consequenstly I need the contributions from those who are experts in the field, whether they are paediatricians, nurses who work in neonatal intensive care units or work in the allied health care professions sector. Without the input from these people this project would not have been possible. Their effort is even more appreciated as this was done in addition to their normal work load. This project would not have been possible without the support of my friends and colleagues, Proff. Hanneretha Kruger and Magdaleen Swanepoel. My sincere thanks go to Nico Ferreira for his

[2] Booklet 13.Published in Pretoria on 29 May 2007.

[3] Carstens P and Pearmain D *Foundational Principles of South African Medical Law* (2007) 229.

efforts to ensure that the footnotes are consistent and in the prescribed style, for the compilation of the bibliography and a list of abbreviations.

It is sincerely hoped that this document will help physicians and parents alike, in making decisions regarding the health care of their patients or offspring pre-discharge and post-discharge.

TWO CONTRIBUTIONS FROM PARENTS WHO HAD PREMATURE BABIES

This document commences with two contributions from two mothers whose babies were born prematurely in order to highlight the different emotions and problems experienced in two different scenarios. The first contribution is from a mother whose baby survived and the second one from a mother who had to make a decision to withdraw life-sustaining treatment. In the former the problems commonly experienced with babies born prematurely, but who survive, are set out. In the latter the emotional trauma when the decision has to be made to withdraw life-sustaining treatment is explained.

1 PROBLEMS EXPERIENCED BY PREMATURELY BORN CHILDREN POST-DISCHARGE

These children are often perceived as being naughty and disruptive; however, they are neither naughty nor disruptive. Their brains function differently from that of full term babies. They hear sounds or noise differently than we do. In short, they experience the world very differently.

They need structure, borders, time settings and a lot of parental support. Only one activity at a time should be focused on until it is completed.

They must be kept busy by doing various exercises, for example swimming and cycling so that they can get rid of excess energy.

1.1 ADHD

This is the most common neurobehaviourial disorder affecting children. The extent of the problem depends on how early it is diagnosed and treated. Early intervention can help to prevent the devastating effects of underachievement, poor self-esteem and, in the long term, possible delinquent behaviour.

Does the following sound familiar?

- My child has been called disruptive
- He does not think before he speaks or acts
- He is easily distractible and struggles to concentrate
- The diagnosis was made by a multi-disciplinary team
- He is currently on medication, however, he has to be evaluated by the paediatric neurologist annually

1.2. Other problems

My son, Justin, does not like very loud sounds, for example, motorboat engines and very loud music. His sense of touch is very sensitive, therefore clothing must be loose fitting and made from cotton fabric, if possible; all labels must be removed from clothes.He does not like hugging; he will come and ask for a hug, but this is done on his own terms. Gross motor development and coordination are weak, resulting in experiencing difficulty in activities such as playing ball games and running.

1.3. School

When Justin was born, the neonatologist warned us that he would experience problems at school. The neonatologist's prediction turned out to be true, especially when it comes to attention span and finishing a task. He does read, however, it is not up to standard, neither does he always comprehend what he reads – comprehensiontests are very difficult to complete. Connections must be made to help him understand and learn some work, for example, dark clouds mean rain and thunder. He is very impatient and cannot wait his turn to answer a question. He has an excellent memory when it comes to things he likes and that is interesting to him, for example, whales. He will gather all possible information about whales, but he does not like Maths so he will do everything to avoid Maths.

Children born extremely prematurely find it difficult to cope in mainstream classes, the tempo and the volume of work are too much; teachers do not have time to spend with these children individually. They need special classes, where the

curriculum has been adapted to suit their needs. They may not be academically gifted but they are very gifted with their ability to work with their hands, they are very practical.

Currently he is in Suiderberg School, which is a school for learners with special Education needs. The current curriculum is adapted from the national curriculum.The children are taught to work with their hands, such as doing woodwork.

Reading is a major concern, as is Maths, like basic addition and subtraction. Handwriting needs to be worked at daily; in order to differentiate between upper- and lowercase letters. He has a resistance against doing homework. The school does not give homework to be completed at home because of the demographics of the school. We have to do additional work at home, because the academic work done at school is too little.

Talking is not a problem; he can speak well in his mother tongue and is able to help himself in English. He is not able to perform more than one task at a time. A major concern for me is the capabilities of the learners in the classroom. The teacher has to conduct class in both English and Afrikaans, which is time consuming and this results in a learner like Justin not being able to pay attention.

He is very friendly and likes to speak to people, and if he likes somebody, he will tend to stick to that person. Unfortunately not everyone is tolerant and patient and other children tend to be nasty. I have seen and experienced that children with special needs do not understand jokes nor can they tell a joke. If they can see a joke virtually happen then they will laugh, the same applies when somebody is sarcastic.

It is an on-going effort to teach and prepare him to enter the labour market.

Engela Goosen

The following is an honest description from a mother, who had to make the difficult decision to have life support withdrawn from her premature baby and the traumatic experience following this decision:

2 EXPERIENCE OF A MOTHER WHO HAD TO DECIDE TO WITHDRAW LIFE-SUPPORT OF HER PREMATURELY BORN BABY

On 19 July 2012, our baby, William James, was born prematurely at 30 weeks' gestation period. Our firstborn. Our son. A handsome, fiery redhead. Beautiful. Perfect. And very sick.

William lived for 19 days in the neonatal intensive care unit and on 6 August 2012, on the advice of our minister and William's team of doctors, my husband and I made the decision to take William off life support. He passed away that afternoon.

The 19 days that William spent with us were filled with joy, anguish, hope, sorrow, love, guilt, confusion and anger. In the days that followed, I have taken and still continue to draw much comfort from the knowledge that in William's short time with us, he was loved by us beyond measure, treated with dignity, that he had the best medical care possible, and that we had the support we needed to make decisions in William's best interests.

These days were ugly. And the time that followed, once the shock of his passing wore off, even worse. No matter what the circumstances under which your baby is born, their prognosis, the length of time which they spend in hospital, whether you must say goodbye, or whether you are able to take your baby home - all of these experiences involve trauma, loss, and grief. For all of them are not what you expected, not what you dreamed of or planned for, and they involve suffering, illness (perhaps prolonged) and maybe even death for your baby. The impact on your baby, you, your partner, your relationship, your children and your family is indescribable and lasting.

There is no predictable, set or perfect way to deal with this trauma. All cases involve their own peculiarities and human frailties. And it goes without saying that the best interests of the baby in each case are paramount.

But what these guidelines seek to do, which I as a parent whole-heartedly support, is to give parents the support and information that they need to make the best possible decisions for their baby, and thereby be the best possible parents that they can be. They seek to give guidance to medical professionals, care-givers (both in and out of hospital) and administrators alike as to how to interact with, communicate and support, the parents of an unwell baby. Parents need medical professionals and other staff to act ethically and with care, to be transparent and honest, to work as a team to ensure that parents at all times have access to the information that they require, that their concerns are understood and that they understand what is going on. Parents and their baby should be treated with respect and with the understanding that a baby is not a bed number or a type of illness, but a person, a child, a member of a family.

It is with this in mind that I hope you read, and where relevant, implement these guidelines. They are, I believe, a living document, that will require on-going discussion and where necessary, revision, to make sure that they keep pace with our growing understanding of ethics, medical science and trauma, and most importantly - the needs of the baby and his or her family.

Aimée Girdwood

SECTION A

LEGAL AND ETHICAL ISSUES IN NEONATAL INTENSIVE CARE

CHAPTER 1

(Magdaleen Swanepoel and Carina van der Westhuizen)

BIOMEDICAL ETHICS

1.1 ETHICAL ISSUES IN NEONATAL CARE

1.1.1 Introduction

Before considering the biomedical ethics pertaining to preterm infants and critically ill neonates, one should look at ethics in general. There are various definitions of ethics. According to Strauss, "ethics can be defined as the science of the rules of moral conduct which should be followed because they are good in themselves. Ethics involves the rational study of preferences; therefore it provides a basis for the making of value judgments."[4] The standard definition of ethics is: "the philosophical study of morality".[5] At first glance it would not seem as though ethics are applied in the decision-making process, and moreover, different people might support different ethical views or philosophies. Even though different people might apply different ethical theories in the decision making process, they might still eventually come to the same conclusion. As different people have different ethical views, courts will not base their decisions on ethical principles, but rather on legal principles that will be applied equally to all people. However, Bryant, Baggot LaVelle and Searle are of the opinion that ethics guides our decision-making and leads us to make the best decision in a particular situation.[6] For this reason ethics cannot simply be ignored.

Medical technology, skills and expertise have advanced to such an extent over the last couple of decades that more babies survive, albeit with long-term morbidity. These medical advances have made it increasingly necessary to consider and develop the biomedical ethics pertaining to this vulnerable group. Biomedical ethics provides a theoretical framework within which health care professionals

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4 Strauss SA "Ethics and the law in South Africa" (1987) *South African Journal of Continuing Medical Education* 21.

5 Audi R (ed) *The Cambridge Dictionary of Philosophy* (1999) 284.

6 Bryant J *et al Introduction to Bioethics* (2005) 18.

should make decisions and act.[7] Although biomedical ethics cannot provide all the answers in terms of what is right and what is wrong in each case, it nevertheless lays down the principles on which decisions should be based.[8] The ethical theories can assist us in drawing a line between what is good what is not, between which actions are morally acceptable and which are not.

The principal ethical theories, namely deontology, utilitarianism and virtue ethics will be discussed. This will be followed by a brief discussion of the four principles of biomedical ethics, namely beneficence, non-maleficence, autonomy and justice. This section will be concluded with a discussion of the "sanctity of life" versus "the quality of life" principles.

1.1.2 Ethical theories

1.1.2.1 Deontology

Deontology is a duty-based approach to ethics.[9] Followers of this philosophical approach hold that fundamental duties and obligations in medical care should not be breached, irrespective of the consequences.[10] According to Kant, the leading exponent of this philosophy, one should not treat people in a way that is contrary to their wishes and that more emphasis should be placed on obligations rather than rights.[11] This is in line with current views of human rights.[12] A particular relationship creates a special obligation, which in turn is limited to the people in that relationship. Parents have special obligations towards their children, and physicians towards their patients. Parents have to make decisions on behalf of their sick preterm infants and critically ill neonates, while physicians have to provide medical treatment that is both effective and available, but at the same time

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7 Campbell A, *et al Medical Ethics* (2005) 14.
8 Bryant J *et al* (2005) 18.
9 *Idem* 23.
10 Miller G *Extreme Prematurity: Practices, Bioethics, and the Law* (2007) 54; Nuffield Council on Bioethics *Critical care decisions in fetal and neonatal medicine: Ethical issues* (2006) 9.
11 Herring J *Medical Law and Ethics* (2006) 15.
12 *Ibid*.

respect the decisions of the proxy decision makers.[13] However, the autonomy of the decision makers is restricted as they are also obliged not to harm the child.[14]

1.1.2.2 Utilitarianism

Broadly speaking, utilitarianism determines whether an action is good or bad by its outcomes or consequences.[15] A course of action is regarded as morally right if its outcomes or consequences are overall beneficial, leads to happiness and usefulness.[16] The extent to which the consequences are good or bad can be determined by weighing up all the consequences of each alternative course of action.[17] The scales will tip in favour of the course of action that produces "the greatest good for the greatest number".[18] The effect of applying the ethical principle of utilitarianism in critical care decisions would mean that decisions would be made according to the predicted outcome for most neonates.[19]

1.1.2.3 Virtue ethics

In essence this approach postulates that a person's character, and not the consequences of a particular action, is the important factor that motivates his or her decision making.[20] In terms of virtue ethics, the character of the neonate's parents and the health care professionals are important, because this will guide their decision making regarding treatment that will be in the best interests of the preterm baby or ill neonate.[21]

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13 Miller G (2007) 54; NCOB (2006) 54.
14 Miller G (2007) 54.
15 Beauchamp TL and Childress JF *Principles of Biomedical Ethics* (2009) 339.
16 Bryant J *et al* (2005) 23.
17 Herring J (2006) 12; Holland S *Bioethics. A Philosophical Introduction* (2003) 205; Miller G (2007) 55.
18 Beauchamp TL and Childress JF (2009) 340; Campbell A *et al* (2005) 5; Herring J *Medical Law Bioethics, and the Law* (2007) 55.
19 Beauchamp TL and Childress JF (2009) 340.
20 Bryant J *et al* (2005) 29; Campbell A *et al* (2005) 8; NCOB (2006) 9.
21 Campbell A *et al* (2005) 8; NCOB (2006) 9.

1.1.3 Principles of biomedical ethics

As mentioned above, decision making in neonatal intensive care is not necessarily based on ethical theories. However, it is essential that the four principles of biomedical ethics are adhered to when any decision, pre- or post-discharge, regarding a neonate is made.

Beauchamp and Childress recognise four principles of biomedical ethics, namely beneficence, non-maleficence, autonomy and justice.[22] These principles are equally important, although autonomy is widely regarded as the primary principle.[23] Autonomy will therefore be discussed first.

1.1.3.1 Autonomy

Autonomy is the freedom of the individual to make his or her own decisions.[24] In essence it means that the doctor or health care professional must respect the final decision of a competent patient regarding his or her medical treatment or non-treatment once the patient has been given all the relevant information.[25] This is a well-established principles in medical law as almost a century ago it was held by the court that a person has absolute security of the person and that the law protects this security.[26]

It is possible that the principle of beneficence[27] and the principle of autonomy may be in conflict.[28] This may happen when the patient's best interests, from the perspective of the patient, are in conflict with the patient's best interests form the physician's perspective.[29] In those cases where there is conflict between the

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22 Herring J (2006) 22.
23 Herring J (2006) 22-23.
24 Brazier M and Cave E *Medicine, Patients and the Law* (2011) 68-70.
25 Beauchamp TL and Childress JF (2009) 103; Beauchamp TL and McCullough LB *Medical Ethics.The Moral Responsibilities of Physicians* (1984) 14, 44; Bryant J *et al* (2005) 29; Carstens P and Pearmain D *Foundational Principles of South African Medical Law* (2007) 229; Strauss SA (1991) 4.
26 *Stoffberg v Elliott* 1923 CPD 148. See also Carstens P and Pearmain D (2007) 202, 500 & 879; Strauss SA *Doctor, Patient and the Law. A Selection of Practical Issues* (1991) 31.
27 See par 1.1.3.3 below.
28 Beauchamp TL and Childress JF (2009) 214; Beauchamp TL and McCullough LB (1984) 23.
29 Beauchamp TL and McCullough LB (1984) 50.

physician's view of the appropriate course of action[30] in a particular case and the patient's view on the matter, the physician has to respect the patient's right to self-determination and his or her right to make his or her own decisions regarding his or her fate.[31]

Whenever there is conflict between the different principles, respect for autonomy is a *prima facie* principle and should therefore be the overriding principle.[32]

The essence of the right to autonomy is that one cannot impose treatment on a patient unless it is necessary to prevent harm to others[33] (for example in the case of contagious diseases). The principle of autonomy carries more weight than the health or life of an individual.[34] However, the principle of autonomy applies exclusively to persons who are capable of acting autonomously, and it cannot apply in the case of neonates who are non-autonomous. In this case decisions regarding treatment would have to be made by surrogate decision makers, like the parents or guardians, who have a special relationship with the child.[35] Since parents' or surrogate decision makers' decisions may be influenced by different factors, such as their own prejudices, emotional, social and economic pressures, they should only come to a decision after careful consultation with all relevant role-players.[36]

The autonomy of parents is restricted: They have a negative duty not to harm their child, and they cannot take decisions regarding the treatment or non-treatment of their children without considering the best interests of their child from the child's perspective.[37]

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30 Herring J (2006) 20.
31 Beauchamp TL and McCullough LB (1984) 42.
32 Beauchamp TL and McCullough LB 15 & 42.
33 Herring J (2006) 23.
34 Strauss SA (1991) 31.
35 Beauchamp TL and Childress JF (2009) 376; Beauchamp TL and McCullough LB (1984) 137-138; Miller G (2007) 54 & 59.
36 Miller G (2007) 60.
37 This is in terms of section 28(4) of the Children's Act 38 of 2005 which reads as follows: "When considering such application the court must take into account the best interests of the child." See also Beauchamp TL and McCullough LB (1984) 138; Miller G *Extreme Prematurity: Practices, Bioethics, and the Law* (2007) 54 & 59.

1.1.3.2 Non-maleficence

The principle of non-maleficence implies that one should avoid inflicting harm on others and is expressed by the maxim *primum non nocere*. This includes both intentional harm and the risk of harm.[38] The principle not to do harm is included in the classical version of the Hippocratic Oath that reads as follows: "I will keep them from harm and injustice."[39] However, non-maleficence is not absolute, since medicine often also does harm, for example in the case of surgery.[40] The principles of beneficence (which means that physicians should act in the best interests of their patients) and non-maleficence should be weighed up against each other.[41] In those cases where treatment would offer no benefit, but would only inflict harm and suffering, and death remains unavoidable, it would be better to discontinue treatment.[42] A physician is under no obligation to continue with treatment that is not beneficial to the patient.[43] This principle has been confirmed in an English case, where it was held that physicians do not have to provide futile treatment and that treatment can lawfully be withdrawn in such a case.[44]

Although it is a debatable point, many scholars distinguish between "killing" and "letting die".[45] There is no moral obligation on a physician to save lives in all cases and at all costs. Biological life should not be preserved when its burdens outweighs its benefits for the patient or when the process of dying is irreversible, and when there is no prospect of continuing with a meaningful life.[46]

In the case of seriously defective neonates the question that should be asked by those responsible for taking decisions on their behalf is whether providing aggressive treatment would be in their best interests.[47] The principle of non-maleficence is not served when the neonate will not survive beyond infancy, will suffer severe pain, and will not be able to participate in meaningful human

38 Beauchamp TL and Childress JF (2009) 8.
39 www.medicinenet.com/script/main/art.asp?articlekey=20909 [accessed 2015-02-14].
40 Brazier M and Cave E (2011) 66.
41 *Ibid*.
42 Beauchamp TL and Childress JF (2009) 8; Miller G (2007) 62.
43 Beauchamp TL and Childress JF (2009) 159.
44 *Airedale Trust v Bland* [1993] AC 789.
45 Beauchamp TL and Childress JF (2009) 172.
46 *Idem* 175.
47 *Idem* 169.

interaction.[48] A decision regarding treatment or non-treatment should be taken with great care and should be sensitive to the burdens as well as the benefits of treatment.[49]

In contrast to the utilitarian approach, according to which a baby born with Down's syndrome would be excluded from virtually all medical treatment, the principle of non-maleficence entails that such a baby should also receive both basic and advanced medical treatment.

Neonates cannot make their own decisions regarding the withholding or withdrawal of treatment, but this principle requires that their best interests should be protected by their surrogate decision makers.[50] It is suggested that vital decisions should be taken by parents after consultation with the physicians and other members of the health care team. Parents would normally act in the best interests of their offspring because of the special relationship that exists between them.[51] By doing this, the principle of non-maleficence would be served.[52] The parents should be given priority as decision makers, and turning to a court should only be considered as a last resort.[53]

1.1.3.3 Beneficence

It is not easy to draw a clear line between beneficence and non-maleficence. Beneficence is more altruistic and has more far-reaching effects than non-maleficence; it requires that positive steps be taken to do good to others.[54] In terms of the principle of beneficence the medical profession has to consider the best interests of his or her patients before embarking on a specific course of action.[55] This principle can be problematic as it could be seen as paternalistic.[56] In

48 *Ibid*.
49 Beauchamp TL and Childress JF (2009) 159.
50 *Idem* 169.
51 *Ibid*.
52 Beauchamp TL and Childress JF *Principles of Biomedical Ethics* (1979) 127.
53 The issue of access to court will be discussed in more detail below.
54 Beauchamp TL and Childress JF (2009) 149-153; Brazier M and Cave E (2011) 65; Slabbert M "Ethics, justice and the sale of kidneys for transplantation purposes" (2010) *Potchefstroom Elektroniese Regstydskrif* 93.
55 Beauchamp TL and McCullough LB (1984) 28; Herring J (2006) 25.
56 Brazier M and Cave E (2011) 65.

terms of this principle the focus is on the positive ethical obligation on a health care professional to help others.[57] The doctor decides whether a patient should be treated and if so which treatment should be given.[58] The purpose of medicine, as envisaged in the Hippocratic Oath, is not – as is often done in modern medicine – to preserve life above everything else.[59] The doctor is only obliged to provide a cure for a disease or injury if there is a reasonable prospect of curing the disease, or the pain and suffering of the disease can be controlled.[60]

In essence the meaning of beneficence in the context of neonatal medical care is that a course of action is taken only if it is in the best interests of the baby.[61] The best interests of the infant should be paramount in the decision-making process, but from the perspective of the infant.[62] Since it is often difficult what the outcome of a particular action will be, it is difficult to determine what the best interests of a neonate are.[63] It should be borne in mind that it is not only the best interests of the neonate that should be taken into account, but also those of his family members, since the decision to treat or not to treat also has certain consequences for the family members.[64]

Followers of the principle of beneficence argue that it is the physician's role to act for the benefit of the patient, even if the patient resists.[65] However, the principle of beneficence cannot be applied without taking cognisance of the autonomy of the patient.[66]

This principle entails that it is important to understand that there is a duty to balance the good that could be done by the provision of benefits and the harm that

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57 Herring J (2006) 25.
58 *Ibid*.
59 Beauchamp TL and McCullough LB (1984) 30.
60 *Ibid*.
61 Miller G (2007) 63. Section 28(2) of the Constitution of the Republic of South Africa, 1996 determines that "a child's best interests are of paramount importance in every matter concerning the child." This is echoed in section 9 of the Children's Act 38 of 2005: "In all matters concerning care, protection and well-being of a child the standard that the child's best interests is of paramount importance, must be applied."
62 Miller G (2007) 63.
63 *Idem* 63-65.
64 Miller G (2007) 6
65 Beauchamp TL and McCullough LB (1984) 79.
66 Brazier M and Cave E (2011) 65.

could be inflicted by doing or not doing good, in other words, by providing or not providing the benefits.[67]

If for example, a neonate is born with a disease like myelomeningocele, the question can be asked whether the principle of beneficence will be served if the neonate is operated on when there is only a slim chance of improvement, but an even greater chance that the infant might not survive at all, or if he or she survives, suffers severe defects.[68] A balancing act should be performed when applying the different bioethical principles: the different principles should be balanced against each other and the interests of society should also be balanced against those of individuals.[69] At the same time the individual's needs must be balanced against the ability of society to provide financial help. In the case of defective neonates, for example those born with myelomeningocele, the question that should be asked is whether the principle of beneficence requires society to pay for such children and whether aggressive treatment should be provided even though the outcome might not be positive. The chances are that these children will not survive, and if they do, they will suffer from serious handicaps.[70]

The principle of non-maleficence requires that the interests of those who cannot decide for themselves should be protected.

1.1.3.4 Justice

The principle of justice in the context of medical ethics requires that treatment should be fair, equitable and impartial for all persons who have the same needs.[71] Regarding extremely preterm infants, this principle dictates that such infants should be treated in the same way as other infants with the same condition.[72] In

67 Beauchamp TL and Childress JF (2009) 136.
68 Beauchamp TL and Childress JF (2009) 149-153.
69 *Idem* 214, 219.
70 *Ibid*.
71 Beauchamp TL and Childress JF (2009) 241-248; Brazier M and Cave E (2011) 66-67; NCOB (2006) 225.
72 Miller G (2007) 68.

practice this would mean that where an extremely preterm infant and a full-term infant both suffer from hydrocephalus, both should be treated in the same way.[73]

However, the principle of justice could be in conflict with the principle of beneficence.[74] It can be argued that the costs involved in providing treatment for an extremely preterm infant in neonatal intensive care, as well as the financial burden the treatment of disabled children places on society, are not justified as this threatens the overall welfare of society and the distribution of resources.[75]

It is suggested that a balancing exercise be performed where the interests of the gravely ill infant are balanced against the costs involved and the subsequent financial burden on society.

1.1.4 Quality of life versus sanctity of life

"Quality of life" versus "sanctity of life" as well as "dignity" and "meaningful life" are fundamental issues that physicians face when they have to decide whether treatment of gravely ill patients is obligatory or optional.[76] The "sanctity of life" doctrine has its origins in the Judeo-Christian tradition and in its extreme form it implies that human life should be preserved no matter what the circumstances.[77] This principle is recognised internationally both in Article 2[78] of the European Convention for the Protection of Human rights and Fundamental Freedoms, 1950, and in Article 6[79] of the International Covenant on Civil and Political Rights, 1966.[80] Followers of this doctrine regard it as morally wrong to fail to preserve or extend human life.[81] As mentioned above this doctrine has a strong religious foundation and followers of this doctrine are of the opinion that all human beings

73 *Ibid*.
74 *Ibid*.
75 *Ibid*.
76 Beauchamp TL and Childress JF (2009) 42, Beauchamp TL and McCullough LB (1984) 123; NCOB (2006) 43.
77 Brazier M "Euthanasia and the law" (1996) *British Medical Bulletin* 321; Brazier M and Cave E (2011) 70-71; Donnelly M *Healthcare Decision-Making and the Law. Autonomy, Capacity and the Limits of Liberalism* (2010) 12.
78 "Everyone's right to life shall be protected by law."
79 "Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life."
80 Harper RS "Medical Treatment and the Law" (1999) *The Protection of Adults and Minors in the Family Division* 12.
81 Holland S (2003) 57; NCOB (2006) 11, 228.

are creatures made in the image of God,[82] therefore all human life, no matter how ill or disabled, is sacred and of equal intrinsic value and should be treated with the same respect.[83] Only God may take the life of one of his creatures.[84]

In terms of this doctrine treatment should always be provided no matter how hopeless the case may be, how disabled the infant may be or whatever the cost.[85]

Beauchamp and McCullough suggest the capacity for social relationships should be the minimum standard when deciding whether treatment should be optional or obligatory.[86] This would imply that an anencephalic baby should not be treated, while a baby born with Down's syndrome would be entitled to treatment.[87] In an English case, the so-called *Bland* case the House of Lords per Lord Keith held that the sanctity of life principle is not violated when treatment that will only prolong suffering is withdrawn or withheld, but that sanctity of life is violated when active measures are taken to deliberately end life.[88]

Beauchamp and Childress are of the opinion that once it becomes clear to the medical team that the treatment provided is merely life-prolonging, they may change to palliative care.[89] Providing palliative care would afford the infant the opportunity to die with as little discomfort as possible and with dignity.[90] This would also be in line with section 10 of the Constitution of the Republic of South Africa, 1996,[91] as the right to dignity is one of the key values entrenched in the Constitution.

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82 Genesis 1:26.
83 Holland S (2003) 61; NCOB (2006) 11, 228.
84 Holland S (2003) 63.
85 Cohen LG *Before Their Time: Fetuses and Infants at Risk* (1990) 58.
86 Beauchamp TL and McCullough LB (1984) 125.
87 *Idem* 124-125.
88 *Airedale NHS Trust v Bland* [1993] AC 789 at 859: "[The principle of the sanctity of life] does not compel the temporary keeping alive of patients who are terminally ill where to do so would merely prolong their suffering. On the other hand it forbids the taking of active measures to cut short the life of a terminally ill patient."
89 Beauchamp TL and Childress JF (2009) 189.
90 *Ibid*.
91 The right to dignity.

The doctrine of “sanctity of life” is contrasted with “quality of life”. In the case of the latter neither an absolute right to life, nor a duty ro preserve it, is recognised, but the question is asked whether it is a life worth preserving in terms of its quality.[92] It is questionable whether one can make value judgments regarding which lives are worth protecting, since people have different perceptions and views on what constitutes a life worth living and protecting.[93]

It is suggested that a life where there is potential for human interaction be preserved at all costs opposed to mere metabolic life that should not be preserved at all costs.

In the case of extremely preterm infants and critically ill neonates there are circumstances in which providing or continuing treatment to keep the infant alive would lead to unbearable pain and suffering; in such instances there would be no moral obligation to preserve that life.[94]

The Nuffield Council on Bioethics suggests that the concept of “intolerability” should be the criterion in determining whether life should be preserved or not.[95] According to the Working Party of the Nuffield Council on Bioethics, “intolerability” has three meanings, namely “no chance”, “no purpose” and “unbearable”.[96] This can be explained as follows: If providing treatment offers no chance of survival, except for a short period of time, the best interests of the baby should be at the heart of a decision concerning palliative care and a peaceful death, instead of aggressive treatment.[97] Futile and distressing interventions that can only prolong life and delay death would result in unbearable suffering.[98] When the infant suffers severe pain that cannot be relieved, is incapable of having meaningful interactions with other human beings and will not be able to have an independent existence, it

92 NCOB (2006) 11.
93 *Idem* 12.
94 *Ibid*.
95 *Ibid*.
96 *Ibid*.
97 Beauchamp TL and McCullough LB (1984) 138-139; NCOB (2006) 12.
98 NCOB (2006) 12.

is doubtful that prolonging suffering by keeping the infant alive would serve any purpose.[99]

In the case of an extremely preterm infant with brain damage, judgments regarding the quality of his or her life and his or her best interests should be from the perspective of the disabled infant.[100] The Royal College of Paediatrics and Child Health (RCPCH) mention in their report that people who are living with disabilities can still enjoy quality of life and they suggest that a distinction be drawn between those with disabilities who are able to live meaningful lives and those who are incapable of human interaction.[101]

Since it is difficult to make a judgment on behalf of infants who cannot express themselves, the best interests argument should be employed in order to determine whether the benefits outweigh the burdens of the proposed treatment.[102] It can be very difficult to make decisions regarding the treatment of critically ill neonates when the prognostic evidence is uncertain.[103]

In conclusion it can be said that although it is not always certain what the prognosis in a particular case might be, the overriding factor that should be considered, is whether the baby will be capable of human interaction.

1.1.5 Conclusion

Ethical principles as set out above might be the last thing on the minds of those who have to make critical care decisions, and when considered in isolation, might not appear to offer practical solutions to the dilemmas in which parents and health care professionals might find themselves when decisions have to be made about the health care of a premature or critically ill neonate.[104] Health care professionals might not be deliberately taking different ethical principles into consideration when

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99 *Idem* 12-13.
100 Miller G (2007) 84.
101 Guidelines for Good Practice: *Management of Neonatal Respiratory Distress Syndrome*. December 2000. Royal College of Paediatrics and Child Health 24-25.
102 Miller G (2007) 80.
103 *Idem* 84.
104 NCOB (2006) 9.

making critical care decisions, neither does everybody subscribe to the same ethical theory, yet everyone has a sense of what is morally right in the circumstances. In spite of their differences, different people with different moral views might eventually arrive at the same decision.[105]

[105] *Idem* 10.

CHAPTER 2

(Carina van der Westhuizen)

INTERNATIONAL LAW AND THE CONSTITUTION

2.1 INTRODUCTION

Before consideration is given to South African legislation pertaining to premature babies a perusal of international human rights instruments is necessary, since the protection of human rights operate on both the national and international level.[106] Effect is given to the international human rights instruments that have been drawn up with the purpose of protecting people, especially children.

2.2 INTERNATIONAL HUMAN RIGHTS INSTRUMENTS[107]

The right to life is guaranteed in article 12(1) of the *International Covenant on Economic, Social and Cultural Rights* (hereinafter the ICESC) of 1996. This Covenant also prescribes an extremely high standard of health care to States Parties.

The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

Furthermore the Covenant sets out the steps that are to be taken by States Parties to attain this goal. Article 12(2)(a) compels States Parties among others, to provide for the reduction of the still birth-rate as well as the infant mortality rate. It also provides for the healthy development of the child.

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106 Mubangizi JC "Public health, the South African Bill of Rights and the socio-economic polemic" (2002) *TSAR* 343.

107 This section was taken from van der Westhuizen CS *A Proposed Framework for the Legal Protection of Premature and Critically-ill Neonates in the Context of South African Child Law* (unpublished doctoral thesis, UFS) (2012).

The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

(a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child.

This is echoed in Millennium Development Goal 4, which has as its aim the reduction of the infant mortality rate.

The right to life is further entrenched in article 6 of the *International Covenant on Civil and Political Rights*, 1966. This article is couched in peremptory language and States Parties are compelled to enact legislation to give effect to this right.

Every human being has the inherent right to life. This right shall be protected by law.

The right to life is echoed in article 4 of the *African Charter on Human and People's Rights*, 1981:[108]

Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of the person. No one may be arbitrarily deprived of this right.

The right to health is mandated in article 16:

Every individual shall have the right to enjoy the best attainable state of physical and mental health.

Although the *Universal Declaration of Human Rights,* 1948, is not a legally binding instrument, it contains provisions that are of importance when considering the protection of premature infants and critically ill neonates. The most fundamental right for a human being, namely the right to life, is guaranteed in article 3.

[108] South Africa ratified the African Charter on Human and Peoples' Rights on 9 July 1996.

The *United Nations Convention on the Rights of the Child* (hereinafter CRC), 1989, is the first international human rights document that gives recognition to the fact that children have special needs that have to be considered and rights that have to be protected. In the CRC the obligation is on States Parties to ensure protection of children. Most of the articles start with the following phrase: "States Parties *shall* …" [my emphasis]. South Africa ratified the CRC on 16 June 1995. The CRC has been ratified by more than 160 countries; the only countries that have not ratified it are the Unites States of America and Somalia.

The preamble to the CRC echoes the *Declaration of the Rights of the Child* in which it is stated that a child needs "appropriate legal protection, before as well as after birth". Article 1 of the CRC broadly defines a child as a human being below the age of eighteen years. The CRC recognises the fact that children need more than mere protection, and that they also have certain rights that need to be protected.[109]

The "best interests of the child" standard is introduced in article 3. The child's right to life is guaranteed in article 6 of the CRC. The second part of this article is of particular importance here, since it imposes an obligation on States Parties to "ensure to the maximum extent possible the survival and development of the child". In article 24 various measures are set out to ensure that children receive the "highest attainable standard of health and … facilities for the treatment of illness and rehabilitation of health". States Parties have an obligation to take appropriate measures to diminish infant and child mortality" in article 24(2)(a). This is in line with Millennium Development Goal 4.

The *African Charter on the Rights and Welfare of the Child* (hereinafter ACRWC) was inspired by the CRC. This charter was ratified by South Africa on 7 January 2000. Article 4(1) contains "the best interests of the child" standard. The CRC introduced the best interests of the child standard; it is extended in article 4 of the African Charter on the Rights, which provides that "the best interests of the child

[109] Sloth-Nielsen J "Ratification of the United Nations Convention on the Rights of the Child: some implications for South African law." (1995) *SAJHR*, 401-420.

shall be the primary consideration".[110] Article 5(1) of the ACRWC provides that every child has the right to life, which must be protected by law and article 5(2) provides that States Parties have a duty to ensure "to the maximum extent possible, the survival, protection and development of the child". Articles 5(1) and 5(2) should be read together with article 14(1) and article 14(2)(a) of the ACRWC which reads as follows:

Every child shall have the right to enjoy the best attainable state of physical, mental and spiritual health.

It also enjoins States Parties so take measures to reduce the infant and child mortality rate. These articles should also not be read in isolation, but should be read together with article 20 which deals with parental responsibilities. The obligation to ensure that the best interests of the child are attained at all times, falls within the ambit of parental responsibilities and rights.

2.3 MILLENNIUM DEVELOPMENT GOALS

The Millennium Development Goals (hereinafter MDG's) are a blueprint agreed upon by all the countries and leading development institutions of the world to achieve eight goals in key areas of global concern.[111] MDG 4, of which the objective is to reduce child mortality, is of particular importance in the writing of guidelines to make critical care decisions and decisions after the neonate has been stabilised. The infant mortality rate is the highest in the poorer countries, with the highest rate among low-income earners. South Africa is one of the few countries in the world where an increase in the infant mortality rate was recorded instead of a decrease.[112]

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110 Davel T "The African Charter on the rights and welfare of the child, family law and children's rights" (2002) *De Jure* 281-296.

111 The eight goals are to (1) to eradicate extreme poverty and hunger, (2) to achieve universal primary education, (3) promote gender equality and empower women, (4) reduce child mortality, (6) combat HIV and AIDS, malaria and other diseases, (7) ensure environmental sustainability and (8) develop a global partnership for development.

112 Schäfer L *Child Law in South Africa.Domestic and International Perspectives* (2011) 48.

Effect has been given to the provisions of international human rights instruments in South African legislation. The first piece of legislation that will be discussed is the Constitution of the Republic of South Africa, 1996.

2.4 THE CONSTITUTION OF THE REPUBLIC OF SOUTH AFRICA, 1996

2.4.1 The right to life[113]

The first right that will be discussed is the right to life, since it is the most fundamental right and without this right all other rights would be meaningless.[114]

In South African law a foetus is not recognised as a legal subject and consequently enjoys no legal protection.[115] On the contrary a neonate, who is born alive, no matter how premature or deformed, is entitled to full protection in terms of the Bill of Rights in the Constitution.

Health care professionals and parents often have to make difficult decisions regarding the treatment of premature or critically ill neonates and all parties might not necessarily agree on what the appropriate course of action in particular circumstances should be.[116] A child's life could be endangered or suffering prolonged by inappropriate decisions relating to his or her health.[117]

In *S v Makwanyane*[118] due consideration is given to the content of "the right to life" by the different judges. They emphasise the fact that the right to life is an unqualified right.[119] *In casu* Justice O'Reagan provides the criterion that can be applied in deciding whether or not to treat a premature a critically ill neonate: "But the right to life was included in the Constitution not simply to enshrine the right to

113 S 11 of the Constitution.
114 Carstens P and Pearmain D (2007) 280.
115 Boezaart T "Child law, the chid and South African private law" in Boezaart T (ed) *Child Law in South Africa* (2009) 4-5; Heaton J *The South African Law of Persons* 4ed (2012) 4-5; Kruger JM and Skelton A (eds) *The Law of Persons in South Africa* (2010) 22-23.
116 Fortin J *Children's Rights and the Developing Law*.3ed (2009) 363.
117 *Ibid*.
118 1995 (3) SA 391 (CC).
119 Chaskalson at par [39], Ackerman at par [157], Sachs at par [350], [351] and [354].

existence. It is not life as mere organic matter that the Constitution cherishes but the right to life: the right to life as a human being, to be part of a broader community, to share in the experience of humanity."[120]

When a neonate is born alive, he or she gains legal subjectivity and is entitled to full protection in terms of the Bill of Rights, which would include the right to life. On the one hand this would imply that a neonate be kept alive by whatever means possible. On the other hand, if it is certain that a neonate will never be able to live life as a human being, be part of a broader community and will not be able to share in the experience of human life; such a baby should also have the right to die with dignity.[121] The same principle applies if medical treatment will not be beneficial, but will only prolong suffering.

However, like any other right in the Bill of Rights, the right to life can be limited. This question came under scrutiny in *Soobramoney v Minister of Health, KwaZulu-Natal*[122] where the Court confirmed that the right to life does not include the right to evade death.[123] The state cannot be expected to prolong the life of an individual indefinitely if there is no hope of recovery since there are not sufficient resources available and, moreover, the available resources should rather be utilised for those individuals who can benefit from medical intervention.[124]

However, in the case of premature and critically ill neonates, it could be problematic, since it is not always clear what the outcome of the proposed treatment will be, whether the treatment will be beneficial or whether it will merely prolong the life of the neonate. It is suggested that the neonate be given the opportunity to prove whether he or she will survive, before aggressive treatment is provided.

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120 *S v Makwanyane*1995 (3) SA 391 (CC) at par [326].
121 Fortin J (2009) 376.
122 1998 (1) SA 765 (CC).
123 Carstens P and Pearmain D (2007) 27.
124 *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 (1) SA 765 CC at par [11]. See also Carstens P and Pearmain D (2007) 27.

The standard of health care for children is neither defined in the National Health Act,[125] nor the Children's Act.[126] Neonates admitted in public hospitals will not receive the same treatment as those admitted to private hospitals due to a lack of resources in the public sector. This is discriminatory against those whose parents do not have the means to pay for expensive treatment at private hospitals nor contribute to a medical aid fund.

Since the right to life is such a fundamental right, every decision regarding the treatment, withholding or withdrawal of treatment, should be taken bearing this right in mind. It has been argued that health care should be provided if it has a beneficial effect, however minimal and the cost involved in treatment should be irrelevant.[127] This would also be in line with provisions in international human rights instruments. However, once it becomes clear that treatment is futile and merely prolonging suffering, it is suggested that it be withdrawn. This should only be done after consultation with the parents or guardians of the neonate.

The right to life is closely connected to the right to dignity and these rights are often called "twin rights".[128] The right to dignity will subsequently be discussed.

125 61 of 2003.
126 38 of 2005.
127 Ngwena C "Access to health care as a fundamental right: the scope and limits of section 27 of the Constitution" (2000) *Journal for Juridical Science* 1-32.
128 Currie I and De Waal J *The Bill of Rights Handbook* (2014) 258.

2.4.2 The right to dignity[129]

The right to dignity of a child is given protection in the CRC and this right is also entrenched in the Constitution. Carstens and Pearmain point out that the rights to life and dignity are diminished by poor health.[130] If a person is no longer able to enjoy quality of life, his or her dignity is also impaired.[131]

If it becomes clear that a critically ill neonate will never be able to enjoy quality of life and will never be capable of human interaction, the neonate should be allowed to die with dignity.

2.4.3 The right of access to health care[132]

In article 24(1) the CRC recognises the fact that it is essential for a child to be in good health in order to reach his or her full potential.[133] The CRC uses peremptory language (i.e. by using the word "shall") in article 24 to ensure that no child is deprived of his or her right of access to health care services. Article 24(1)(a) also places an obligation on States Parties to reduce the infant mortality rate and in article 25(1)(b) the emphasis is on the development of primary health care services for children.

Neither "health care services" nor the quality of health care or emergency treatment as it appears in the Constitution is defined.[134] It has been suggested that it should include proper medical care, prevention and diagnosis of diseases and vaccination.[135]

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129 S 10 of the Constitution.
130 Carstens P and Pearmain D (2007) 29.
131 *Ibid*.
132 S 17(1)(a).
133 Fortin J (2009) 363.
134 Mubangizi JC "Public health, the South African Bill of Rights and the socio-economic polemic" (2002) *TSAR* 344.
135 *Idem* 344-345.

It is recommended that all health care services must be provided for free to children under the age of six and not only primary health care services.[136]

The right to health care services and emergency medical treatment may be applied horizontally as well as vertically. The horizontal application places a duty on private and public hospitals, as well as on health care professionals to provide treatment.[137] Likewise, the vertical application places a duty on the government to provide medical treatment.[138]

Like all other rights the right to health care services is also subject to the internal limitation clause in section 27(2) of the Constitution[139] in terms of which health care has to be provided if the state has enough available resources. Section 11 of the Children's Act[140] deals with children with disabilities and chronic illnesses. Premature, especially extremely premature babies are likely to suffer from some form of physical or mental disability should they survive, which means that they will be entitled to specialised care as envisaged in this section. Likewise a critically ill neonate, who might also be left physically or mentally disabled if he or she survives the illness, should also be entitled to specialised care as envisaged by section 11 of the Children's Act. To provide these infants with specialised care would also be in line with the provisions of the CRC.

2.4.4 The right to emergency medical care[141]

Emergency medical treatment has been defined as follows: "Emergency medical treatment refers to situations where medical treatment is necessary because a person's life or health is in serious danger as a result of disease, injury or ill health."[142]

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136 Bücher-Eveleigh M and Nienaber A "Gesondheidsorg vir kinders: Voldoen Suid-Afrikaanse wetgewing aan die land se verpligtinge ingevolge die Konvensie oor die Regte van die Kind en die Grondwet?" (2012) *PER* 114-115.

137 Mubangizi JC (2002) 345.

138 *Ibid*.

139 This section reads as follows: "The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights." Liebenberg S *Socio-Economic Rights: Adjudication under a Transformative Constitution* (2010) 96.

140 38 of 2005.

141 S 27(3).

142 McQuoid-Mason D and Dhai A *A-Z of Medical Law* (2011) 178.

It is standard practice to resuscitate an ill neonate shortly after birth when his or her life seems to be in danger. This is usually done before decisions regarding treatment can be made. It is suggested that in terms of section 27(3) of the Constitution these facilities should be expanded where necessary to meet the demand.

Should a situation arise where a public hospital cannot provide the necessary emergency treatment for a neonate, private hospital facilities should be made available to the public hospital. In such a case the state should be held responsible for the expenses to the private hospital.

2.4.5 The best interests of the child[143]

All the rights mentioned above, namely the right to life, the right to dignity, the right to right of access to health care and the right to emergency medical care, should be read together with section 28(2) of the Constitution which provides that the best interests of the child are of paramount importance in all matters concerning the child.

The factors which should be taken into consideration when determining the best interests of the child are listed in section 7 of the Children's Act.[144] In terms of section 9 of the Children's Act[145] the best interests should be taken into account in all matters affecting the well-being of a child and should therefore be used as a guideline when decisions are made regarding the treatment, continuation of treatment or withholding of treatment of critically ill neonates. The best way to make a decision that will be in the best interests of a neonate will be to weigh the benefits and burdens of the proposed treatment.[146]

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143 S 28(2).

144 38 of 2005.

145 38 of 2005.

146 A balance sheet of the benefits and burdens of the proposed treatment was drawn up by the court in *Re J (A Minor) (Wardship: Medical Treatment)* [1991] 2 WLR 140 (CA). See also Moore DJ "Medical surrogacy mediation: expanding patient, family, and physician rights and reformulating the Virginia Health Care Decisions Act" (2002-2003) *Virginia Journal of Social Policy & the Law* 417.

However, if there is disagreement between health care professionals and parents on what exactly would be in the best interests of their offspring, it is suggested that the High Court as upper guardian of all minors in South Africa be requested to step in. The High Court should then make the decision of what is in the best interests of a particular neonate. This is a measure that should only be pursued as a last resort and only in exceptional circumstances as parents or guardians are in a better to judge what in the best interests of their children and a judgment by the High Court will also impact on the autonomy of parents or guardians.

It is important to note that the best interests of children standard has been introduced to protect children and not parental rights. The introduction of this standard introduced a shift away from parental rights with the focus now on the rights of children.

Children, especially neonates, have different health needs from adults. The health needs of premature and critically ill neonates also differ from those of healthy neonates. If premature babies and critically neonates do not receive timeous and appropriate medical treatment, it can have serious consequences and can even be fatal for the patient in question.

Nowadays premature and critically ill neonates can be kept alive for longer due to the advancement made in medicine and technology. However, this may also increase the risk of being severely handicapped and even with the possibility that they will not be able to enjoy personal interaction. Medical treatment might not be always in the best interests of a particular neonate as treatment could cause more pain than non-treatment. The irony is that the better the cognitive function of the baby, the more discomfort and suffering that neonate will experience when on life support.[147] It is suggested that a balancing exercise be performed before a decision regarding treatment or non-treatment is made, where the advantages and possible positive outcome of the treatment are weighed against the disadvantages and pain that the treatment will provide.

[147] Fortin J (2009) 380.

In South Africa with its unique health care system which operates as a private health care system as opposed to the public care system, one finds that often there is a discrepancy between the treatment provided in these two systems. On the one hand, in the private health care system and private hospitals, premature babies and critically ill neonates will receive the best treatment possible as long as the parents or medical aid can fund the treatment. On the other hand, those who cannot afford private medical treatment will be admitted to public hospitals where the quality of treatment might not always be of the same standard as that in a private hospital due to a lack of resources. It should be emphasised that the standard of care is not necessarily of an inferior quality in all public hospitals, however, they often have to treat more patients than their capacity allows.

Neonates do not have a voice of their own; consequently their parents have to exercise their discretion regarding treatment. This would include decisions whether to treat, continue with treatment or even to withhold or withdraw treatment.

The best interests standard of the neonate cannot be taken in isolation and that of the other family members, especially other siblings should also be considered.[148] Ultimately the combined interests of other family members may outweigh the interests of a particular neonate.[149] The best interests of the different parties should be weighed up before a final decision is made.

148 Clark B "My right to refuse or consent: the meaning of consent in relation to children and medical treatment" (2001) *THRHR* 617.

149 *Ibid*.

CHAPTER 3

(Carina van der Westhuizen)

SOUTH AFRICAN LEGISLATION

3.1 THE NATIONAL HEALTH ACT 61 OF 2003

The National Health Act was enacted to give effect to section 27 of the Constitution of the Republic of South Africa, 1996.[150] The Act sets out its objectives, which are among others, to protect, respect, promote and fulfil the rights of vulnerable groups, such as women, children, older persons and persons with disabilities.[151] Although no definition of "neonate" is provided in the Act, the people whom this Act intends to protect is wide enough to include premature babies and critically ill neonates. It is a well-known fact that these infants would often be left with disabilities, should they survive, and consequently ought to be protected under the Act. Although the Act does not clearly state what form the protection should take, it provides that children under the age of six years are eligible for free health services.[152] It is uncertain whether these health services are limited to primary care and emergency treatment, or whether they also include specialised treatment, for example in neonatal intensive care units. Certain academics argue that all medical services should be available to children under the age of six years at public hospitals, although the standard of the medical service is not defined.[153]

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150 (1) Everyone has the right to have access to –
(a) health care services, including reproductive health care;
(b) sufficient food and water; and
(c) social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.
(2) The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.
(3) No-one may be refused emergency treatment.

151 Section 2(c).

152 Section 4(3)*(a)*: "subject to any condition prescribed by the Minister, the State and clinics and community health care centres funded by the State must provide –
(a) pregnant and lactating women and children below the age of six years, who are not members or beneficiaries of medical aid schemes, with free health services."

153 Büchner-Eveleigh M and Nienaber A (2012) 114-115.

The government is only obliged to provide the minimum core of health services and moreover, the provision of health care services is subject to the availability of resources.[154] As health care services are such an important component of the right to life, the provision of health care should not be limited to the availability of resources. This is especially true in the case of the treatment of neonates, including premature and critically ill neonates.

3.2 THE CHILDREN'S ACT 38 OF 2005

3.2.1 Consent to medical treatment

It is a well-established principle in South African law that should a doctor give medical treatment or perform an operation without the necessary consent, this amounts to assault for which a delictual claim for damages may be instituted against the doctor and he or she may also be criminally prosecuted.

In the case of minors below the age of 12 year (to which group neonates would also belong) the question of consent is regulated by section 129 of the Children's Act. Section 129(1) provides that consent is needed before a child can be subjected to medical treatment or an operation. In terms of section 129(4)[155] a parent, guardian or care-giver may consent to medical treatment. This form of consent is subject to section 31, which deals with major decisions involving the child. Of particular significance is section 31(2)*(a)* which provides that "[b]efore a person holding parental responsibilities and rights in respect of a child takes any decision contemplated in paragraph *(b)*, that person must give due consideration to any views and wishes expressed by any co-holder of parental responsibilities and rights in respect of the child". Decisions regarding the medical treatment of a child are major decisions that involve the child, and therefore co-holders of parental responsibilities and rights need to consult with each other when making

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154 Section 3. See also section 27(2) of the Constitution.

155 The parent, guardian or care-giver of a child may, subject to section 31, consent to the medical treatment of the child if the child is –
(a) under the age of 12 years; or
(b) over that age but is of insufficient maturity or is unable to understand the benefits, risks and social implications of the treatment.

these decisions. Any decision should only be made after considering the best interests of the child.

In urgent cases the superintendent or person in charge may consent to medical treatment or surgical intervention.[156] This section sets out which circumstances should be regarded as an emergency. This is in line with section 6(4)*(b)*[157] which provides that a delay should be avoided as far as possible in any matter concerning a child. In this respect the Children's Act differs from the National Health Act, which provides that a health service may not be provided unless a delay in medical treatment would prove to be fatal to the patient or cause irreparable harm to his or her health and the patient has in no way, neither tacitly, impliedly or by conduct refused service.

The Children's Act also makes provision for the Minister of Social Development to consent to medical treatment in cases where the parents unreasonably withhold permission, cannot give consent, cannot be traced or are deceased.[158] In this instance the Children's Act provides that the High Court or a children's court may consent to medical treatment. This should be the preferred route to follow as it causes the least delay. Such consent can be obtained by way of an urgent application to the High Court.

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156 Section 129(6): "The superintendent may consent to the medical treatment of or a surgical operation on a child if –
(a) the treatment or operation is necessary to preserve the life of the child or to save the child from serious or lasting physical injury or disability; and
(b) the need for treatment or operation is so urgent that it cannot be deferred for the purposed of obtaining consent that would otherwise have been required."

157 In any matter concerning a child
(b) a delay in any action or decision to be taken must be avoided as far as possible.

158 Section 129(7) reads as follows:
The Minister may consent to the medical treatment of or surgical operation on a child if the parent or guardian –
(a) unreasonably refuses to give consent or to assist the child in giving consent;
(b) is incapable of giving consent or of assisting the child in giving consent;
(c) cannot readily be traced; or
(d) is deceased.

3.2.2 Children with disabilities and chronic illnesses: Section 11 of the Children's Act

In section 11 of the Children's Act some form of protection is afforded to children with disabilities and chronic illnesses. Premature and critically ill neonates would fall into this category, although they are not specifically mentioned in the Act. Section 11(1)*(a)* provides that in the case of a child with disabilities "due consideration" be given to the provision of special care for this vulnerable group. Section 11(1)*(d)* makes provision for a child with disabilities and his or her care-giver to be guaranteed the right to "necessary support services." However, no definition of the term "support services" is provided in section 1, neither is it defined in section 11 of the Act. Furthermore, section 11(2) makes provision for "special support" for children suffering from a chronic illness. Neither section 1 nor section 11 of the Act provides a definition of "support services". The protection afforded to children with disabilities and chronic diseases is primarily aimed at providing a child with some form of disability with "education, training and health services" with the purpose of preparing him or her for employment when he or she reaches adulthood.[159]

In section 106(2)*(c)* further protection is given to this vulnerable group of infants in the form of therapeutic programmes. Once again, this is not defined and consequently it is uncertain in which circumstances "therapeutic programmes" should be provided and what exactly these therapeutic programmes would entail.

[159] Davel CJ and Skelton A (eds) *A Commentary on the Children's Act* (2007) 2-16.

CHAPTER 4

(Carina van der Westhuizen)

WHEN THERE ARE DISPUTES IN THE NICU: LITIGATION OR MEDIATION?[160]

4.1. INTRODUCTION

It often happens that health care providers and parents do not agree on the appropriate course of action in the particular circumstances. Conflict might arise on the question whether treatment should be provided, withdrawn or withheld. The conflict might not only be between parents and doctors, but between the neonate's parents. The question is what should be done in the case of conflict. There are two available options in South Africa, namely mediation and litigation. These will be discussed below.

4.2 MEDIATION

Mediation has been conducted successfully in health care matters in the United Kingdom and the United States of America, however, it has not yet been explored in South Africa, especially in matters involving the NICU. When conflict arises between the different parties, it will be to the advantage of the different parties if disputes are resolved by way of mediation rather than litigation.[161] An independent mediator will assist parties to reach a mutually acceptable agreement.

Below is an example from a judgment where mention is made that mediation as a form of alternative dispute resolution has been used in England and Wales in a dispute regarding the treatment of a child.

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160 This section is adapted from the following article: van der Westhuizen CS "The solution to demands made on parents' decision-making in the neonatal intensive care unit: Mediation or litigation?" (2015) *THRHR* 63-79.

161 Canter JM "Nonjudicial alternatives for resolving end-of-life decisions for minors" (2005) *Family Court Review* 532.

Case study:

Portsmouth Hospitals NHS Trust v Wyatt [2005] EWCA Civ 1181 1 WLR 4027.
In this case brief mention is made of mediation, from which it can be deduced that mediation is used in disputes in NICU in England and Wales.

"Only a tiny proportion of consent to treatment cases which come to lawyers end up before court. The vast majority were resolved when additional experts were brought into the case (on either side): when mediators were used, and when the prospects of proceedings focused everyone's mind. All this would be lost if cases could only be brought at the last minute."

The Nuffield Council on Bioethics also recommends that mediation be extended to critical care decisions as there are potential advantages to using mediation in disputes in critical care decisions in neonatal medicine.[162]

"Mediation can be valuable in helping to resolve other kinds of disputes. In family law, it has been used effectively in disagreements between parents about the care of their children following a divorce, although it has proved to be less so when made compulsory. We recognise that disputes involving family law and cases of clinical negligence present somewhat different challenges to those raised by critically care decision making in fetal and neonatal medicine. Nevertheless, there are similarities in that strong emotions are involved."[163]

[162] Nuffield Council on Bioethics (2006) 163.
[163] *Idem* 147.

4.2.1 Legislative foundation for mediation in South Africa

There is a strong legislative foundation that favours mediation in South Africa. Sections 46, 69 and 71 of the Children's Act provide the children's court has the discretion to refer certain matters for mediation in order to settle the matter out of court.[164] These sections point to the fact that it was the intention of the legislator that child-centred disputes be mediated before they go to court.[165] Section 6(4)*(a)* of the Children's Act provides that "an approach which is conducive to conciliation and problem-solving" should be followed. This section also provides that a confrontational approach should be avoided as far as possible when dealing with children. Although these sections do not specifically mention mediation in the case of disputes between parents and health care providers, it provides enough evidence that health care disputes should also be referred to mediation as the child is at the heart of these disputes.

An amendment to the rules regulating the conduct of the proceedings in the Magistrate's Courts of South Africa[166] provides that disputes may be referred to mediation before commencement of litigation or potential litigation in the Magistrate's Court. It may also be referred to mediation after the commencement of litigation but before judgement.[167] Although these rules were drafted for use in the Magistrate's Court, which includes matters in the children's court, it is submitted that those disputes which would normally be heard by the children's court can be referred to mediation.

In terms of the Consumer Protection Act[168] patients (in this case it will be the parents or guardians as surrogate decision makers of the minor patient) are consumers and health care professionals are the service providers or suppliers. Section 70 of this Act provides that if there is a dispute regarding the quality of the service rendered, the matter may be referred to mediation. This is further proof

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164 De Jong M "A pragmatic look at mediation as an alternative to divorce litigation" (2010) *TSAR* 527.

165 *Ibid*.

166 As published in GG No 37448, 18 March 2014.

167 S 75.

168 68 of 2008.

that a dispute between parents or guardians of the neonate and health care providers can be referred to mediation.

4.2.2 The mediation process

The mediator has no decision-making powers, but only assists the parties to reach a mutually acceptable agreement. It is suggested that the mediator should not come from the hospital staff. Furthermore, the co-mediation model should be used in mediation in disputes in NICU. One of the mediators should be a mediator with a legal background, but who is also skilled in bioethics. The second mediator should be someone with a psychological background, such as a psychologist or social worker. The mediator with the legal and bioethical background should ensure that the agreement that is reached is in accordance with sound legal and bioethical principles.[169] The mediator with the psychological background has to deal with the emotional issues in the decision-making process, which is a very important issue in the NICU.

When a decision has been reached by the parties, a memorandum of understanding should be drafted in which the agreement that has been reached is set out. Parties should be advised to make the agreement an order of court as the High Court is the upper guardian of all minors in South Africa. This will also prevent any party being subjected to any criminal proceedings afterwards.

Disputes that arise in NICU are of a private nature and should preferably be kept out of the public sphere. Mediation takes place in a private setting, while the court room is a public setting (unless of course a case is heard *in camera*). Mediation takes place in a private setting, which is a non-threatening environment, while the court room can be intimidating, especially for someone not accustomed to court procedures.

Litigation takes the decision-making powers out of the hands of the parents or guardian of the baby, and consequently compromises the parents' autonomy.

[169] Liebman CB "Introduction to the symposium issue on alternative dispute resolution strategies in end-of-life decisions" (2007) *Ohio State Journal on Dispute Resolution* 13.

Mediation also has the added advantage that it will enhance communication between parents and doctors as they have to meet face to face in the mediation room and are encouraged to communicate.

It is recommended that health care institutions and legal experts alert patients or proxy decision makers to the fact that disputes can be resolved by way of mediation.

4.3 LITIGATION

Mediation is not a magic wand which can be used to resolve all disputes. In cases not suitable for mediation the court can be requested to step in and adjudicate the matter.[170] This should, however, only be done as a last resort. Cases which would traditionally be unsuitable for mediation would be cases where there is a substantial power imbalance between the parties, or where one party is unwilling to mediate. Litigation will also be the route to follow where mediation fails.

To date, the only reported case where there was a dispute between a doctor and parents in South Africa is that of *Hay v B*.[171]

In this case the respondents, the parents of Baby R, opposed an urgent application by the paediatrician, Dr Hay, to administer a blood transfusion in an attempt to save the life of the said baby. The parents as the respondents opposed the application on the grounds that blood transfusions went against the tenets of their religion. They were also concerned about the risk of infection. The court held that the child's best interest was of paramount importance in all matters concerning the child and that the baby's right to life outweighed the parents' right

170 Bierlein M "Seeing the face of the patient: considerations in applying bioethics mediation to non-competent end-of-life decisionmaking" (2007) O*hio State Journal on Dispute Resolution* 87.

171 2003 (3) SA 492 (W).

to religious freedom and ordered that the blood transfusion be administered to the baby.[172]

The principle that parents may not refuse medical treatment or surgery for their children based on their religious beliefs has since been enacted in section 129(10) of the Children's Act.

There seems to be uncertainty among health care professional concerning the consent requirements for medical treatment and surgery. This is regulated by section 129 of the Children's Act. As we are dealing with neonates, the consent requirement for children under 12 years will apply. This means that a parent, guardian or care-giver may consent to the medical treatment of a neonate.[173] However, only a parent or guardian may consent to a surgical operation of a neonate.[174] The superintendent of a hospital may consent to medical treatment or surgery in the case of an emergency and the said treatment or operation is needed to save the life of the child.[175] It should be noted that the superintendent of a hospital cannot give consent to medical treatment or surgery in the case of a dispute between parents and healthcare professionals. The Minister of Social Development can also give consent to medical treatment or surgery when the parent or guardian unreasonably withholds their consent, cannot give consent, cannot be traced or is deceased.[176] This is not the preferred route to follow in the case of an emergency, as the process may take too long when time is of the essence. The best alternative in the case of an emergency will be to approach the High Court by way of an urgent application. A judge is on duty 24 hours a day, seven days a week for urgent applications. Obtaining a court order does not necessarily mean that one has to go to a court room, but an order may also be obtained from the judge on duty in chambers.

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172 *Hay v B* 2003 (3) SA 492 (W) at 494 – 495. See also Dinnie D "Religion and the right to life" (2005) *Without prejudice: South Africa's corporate legal magazine* 33 and McQuoid-Mason "Religious beliefs and the refusal of blood transfusions for children: what should doctors do?" (2005) *THRHR* 315-321.

173 S 129(4) of the Children's Act 38 of 2005.

174 S 129(5) of the Children's Act 38 of 2005.

175 S 129(6) of the Children's Act 38 of 2005.

176 S 129(7) of the Children's Act 38 of 2005.

The issue of costs seems to be problematic for health care professionals in the private sector, but even more so, for those in the public health sector. Lawyers have to do a certain amount of *pro bono* work, which means that any lawyer can be requested to bring the application *pro bono*. A lawyer can also appear *pro amico* and no fees will be charged. Alternatively any person, for example an academic, who has been admitted as an attorney or advocate, may also appear without charging any fees.[177]

In the case of a dispute,[178] it is important that a court order is obtained before any treatment is given or surgery performed to ensure that the health care professional is not subjected to criminal proceedings.

[177] It is interesting that in the *Hay* case (discussed above) no order regarding costs was made.

[178] Or any of the instances mentioned in s 129(7) of the Children's Act.

SECTION B

CLINICAL ASPECTS OF THE DECISION-MAKING PROCESS: PRE-DISCHARGE

CHAPTER 5

(Dini Mawela)

GUIDELINES FOR CRITICAL CARE DECISIONS: PRE-DISCHARGE

5.1 INTRODUCTION

Advances in neonatal medicine in the last 30 years have made it possible for the survival of more and more babies who would have died before. South Africa, however, has a unique health care system, namely a private health care system and a public health care system. On the one hand, the private health care system offers the best medical treatment to those who can afford the expensive rates or to patients who belong to a medical aid fund. In the private health care system treatment is often given for as long as the medical aid funds are willing to pay. On the other hand, neonatal units in the South African public sector are busy, overcrowded and largely under-resourced.

5.2 CARE AT THE LIMITS OF VIABILITY

The definition of viability is complex. While there are global and international definitions of viability, these have to be seen in the context of different countries, health care systems, access to health care and resource availability. The Webster online dictionary defines viability as “having attained such form and development as to be normally capable of surviving outside the mother’s womb”. Viability has also been defined as the ability to sustain life outside the womb, **with or without medical assistance.**

Viability will therefore not only depend on gestational age and birth weight but on other factors as well, like the condition of the infant at birth, the presence of birth defects or lethal anomalies and in many settings on the level and quality of care which can be provided at birth and immediately thereafter.

The rate of survival for babies born too early has been increasing steadily over the past few decades. However, most extremely premature babies still die. Preterm babies at the lower ends of gestation are medically vulnerable. They are at a high risk for early neonatal morbidity like septicaemia, intraventricular haemorrhage (IVH), patent ductus arteriosus (PDA), necrotizing enterocolitis (NEC) and retinopathy of prematurity (ROP). If they survive the prolonged stay in NICU, some of them will end up with adverse neurodevelopmental outcomes including hearing and vision impairments, learning and behavioural difficulties and sometimes cerebral palsy. It becomes necessary to assist healthcare providers to define the level of maturity below which survival and/or acceptable neurodevelopmental outcome are extremely unlikely for each individual baby.

The "limit of viability" is a term used loosely to define a gestational age at which 50% of babies will survive until being discharged from the hospital.[179]

The EPICure study done in the United Kingdom to compare outomes in two birth cohorts, found that in 1995 only 2% of babies born at 22-23 weeks' gestation age were likely survive and up to 40% of those born at 25 weeks of gestation were likely to survive.[180] Data for the EPICURE 2 study in 2006 showed that survival of these extremely premature babies in 2006 had increased overall from 40% to 53% ($p<0.001$) at each week of gestation.[181] Other available data indicate that survival of appropriate-for-age infants <23 weeks' gestation age and <500 g birth weight is extremely unlikely, with virtually no chance for intact survival.[182]

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179 Larcher V "Ethical considerations in neonatal end-of-life care" (2013) *Seminars in Fetal and Neonatal Medicine* 105-110.

180 Costeloe KL *et al* "Short term outcomes after extreme preterm birth in England: Comparison of two birth cohorts in 1995 and 2006 (the EPICURE studies)" (2012) *BMJ* 345: e7676.

181 *Ibid*.

182 Seri I & Evans J "Limits of viability: Definition of the gray zone" (2008) *Journal of Perinatololgy* 28, S4-S8.

5.3 THE "GRAY ZONE"

The so called gray zone is the gestational age that corresponds to major prognostic uncertainty and therefore infants born at this time would present a major problem in making "the best decision".

Babies between 500 and 599 g and at 23 – <24 weeks' gestation age are considered to be in a "gray zone".[183] The international "gray zone" may however differ with what is considered the "gray zone" in the developing world, including South Africa. The recommendation is that when such a baby is born, the parents' wishes are taken into consideration to decide on resuscitation and active life support treatment.

Neonatal mortality rates (NMR) vary among countries, hospitals and units. This may be attributed to various causes including availability of resources - levels of intensive care, lack of certain medical interventions or resuscitation skills, poor maternal antenatal care and disparities of race and socioeconomic status.

Data on survival of preterm babies in developing countries is not well documented. Two studies done in public sector hospitals in Johannesburg, South Africa showed similar rates of survival of infants <1000g . The survival to discharge rate was 32% for infants <1000g cared for at Chris Hani Baragwanath Academic Hospital (2000-2002)[184] and 34.9% at Charlotte Maxeke Johannesburg Academic Hospital (2006-2007).[185] Although it is accepted that gestational age is a better predictor of outcome than weight, in these resource constrained areas it was more practical to document birth weight as most of the pregnant women did not have access to an antenatal dating ultrasound, and on admission a gestational age estimation may not have been done due to lack of experience of the admitting physician or due to work pressure.

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183 *Ibid*.

184 Velaphi SC *et al* "Survival of very-low-birth-weight infants according to birth weight and gestational age in a public hospital" (2005) *S Afr Med J* 95: 504-509.

185 Ballot DE *et al* "Determinants of survival in very low birth weight neonates in a public sector hospital in Johannesburg" (2010) *BMC Pediatrics* 10:30 [www.biomedcentral.com/1471-2431/10/30 Date of access 05 January 2016].

Growth standards are largely derived from international literature and may not be appropriate for our setting. It is also important to note that existing growth data for preterm babies has inherent problems related to how gestational age is determined, but also because of the differences in birth weight of babies born to women in different population groups and women of different socioeconomic status. The table below therefore is only a guide of the expected weight at different gestational ages, assuming that the infants are classified as appropriate for gestational age at birth.

Gest age (weeks)	23	24	25	26	27	28
Birth weight (grams)	500	600	660	760	875	1005

Table 1: Adapted from Beckstrom AC and Woodrum AD: Neonatal ICU issues; Ethics in Medicine[186]

On the basis of available data in the literature, viability therefore can range between 24-28 weeks depending on the country and healthcare setting. In keeping with international trends, from 26 weeks' gestation age or 760g, given that the outlook for these babies at this gestation age is considered to be sufficiently good, we would propose that these babies are regarded as viable and qualify for active resuscitation and treatment in the NICU.

All other babies below this "level of viability" irrespective of birth weight and gestational age should still receive standard neonatal care including warmth and KMC, good nutrition and breastfeeding, supplemental oxygen as needed, intravenous fluids, antibiotic treatment and blood transfusion.

186 Beckstrom AC and Woodrum AD "Neonatal ICU issues" (2014) *Ethics in Medicine*, https://depts.washington.edu/bioethx/topics/nicu.htmal [Date of access 5 January 2016] 51.

It is therefore important for each unit to obtain follow-up data for its own infants. Decisions about viability then can be based on local performance and the actual odds faced by the infant admitted to the individual unit. Knowledge of accurate outcomes data will allow clinicians to make better decisions that are based on evidence.

5.4 ETHICAL DECISION MAKING

The process: Ethical decisions in neonatal care are made on the basis of the baby's clinical condition. The healthcare team makes an evaluation of probabilities of dying or long term disability based on the best evidence before them.

The team that ultimately makes these decisions needs to be as inclusive as possible. The team must include medical doctors, nurses, and other allied professionals with the parents or family being included on the team. The head of the unit or the most senior clinician can be the leader of the team. The clinical information on the case should be presented honestly and openly. The parents or other family members must be allowed to raise their concerns. These should be addressed in a sensitive manner. The role and extent of the parents' involvement in the decision making process will depend on their educational, social, religious and cultural backgrounds. Most parents or family members will look for guidance from the healthcare team and will most likely agree with the recommendations of the healthcare team.

When there is disagreement within the team, either between healthcare professionals themselves or between healthcare professionals and the parents or family member, it may be necessary to adjourn the meeting specifically to gather more evidence. Given more time and evidence, there might be consensus at the next meeting.

In the extreme event where disagreements cannot be resolved, the high court may be requested to step in and resolve the dispute.[187] Such a decision will be taken on what is in the best interests of the baby.

Where multidisciplinary clinical ethics committees have been established, they could provide a valuable contribution to the decision-making process.

5.5 SELECTIVE NON-TREATMENT IN NEWBORNS

Clinical decisions may be made after delivery of a live born infant to either withhold or withdraw medical care. This situation has also been called "letting nature take its course". In most cases these decisions are made once it is decided that death is unavoidable or prognosis is extremely poor. Selective non treatment for certain newborns has been practised for many years in many settings but there is limited data available in the literature about the number of babies who actually die because of this practice.[188] Duff and Campbell[189] were among the first to publish information about moral and ethical dilemmas in the special care nursery, including the withdrawal or withholding of care. There has been an on-going debate around the ethics of selective non treatment since then.

5.5.1 Definitions

Withholding of medical care occurs when a clinical decision is made not to initiate any medical care because death is inevitable and therefore treatment in this case is deemed to be futile.

Withdrawal of medical care occurs when a clinical decision is made that there is no benefit in continuing to provide life prolonging treatment and that any further treatment is not in the best interests of the infant.

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187 See also the section on mediation in par 4.2 above as an alternative to resolve disputes in the NICU. The aspect of disputes between parents or other family members is discussed in detail in paras 4.2 and 4.3.

188 Duff RS & Campbell AGM "Moral and ethical dilmemas in these special care nursery" (1973) *New England Journal of Medicine*, 289; 890-894.

189 *Ibid*.

The decisions to withhold or withdraw medical care have been considered by most ethics authorities, health care providers and legal institutions to be ethically and morally equivalent.

Selective non treatment of newborns generally occurs in clinical situations when infants are considered to be so extremely premature that they have virtually no chance of survival, in infants with recognizable lethal congenital anomalies or for those infants who in the medical team's opinion would likely live a life with significant and unacceptable permanent disability.

When these end-of-life decisions have to be made, there is a general agreement that they should be 'shared' decisions. These decisions should ideally be made by consensus, after open discussion involving the physicians, nurses and other allied health care personnel involved with the day to day care of the patient. The parents and other family members form an integral part of the decision making team. However, such decisions should never be left to the parents and family alone because this may be too great a burden for them. Any such discussions and decisions should be documented clearly in the patient's clinical notes.

5.6 MANAGEMENT AFTER END-OF-LIFE DECISIONS

The decision to withhold or withdraw medical care should be followed by an expressed intention to continue providing appropriate medical care for the baby, whose death is inevitable. The main focus of treatment after end of life decisions would be to provide comfort and to relieve pain and suffering. There should be very clear decisions made to limit the many uncomfortable and painful procedures that are done in the NICU like multiple peripheral line insertions, heel pricks, blood sampling, intubation and suctioning.

The approach to palliative care in neonates follows a few basic principles.

- Anticipatory discussion with the parents and family – This is most likely to happen if it is known during antenatal care that the baby is unlikely to be treated after birth usually due to a lethal congenital anomaly or due to extreme prematurity. The parents and/or family would then have had an opportunity to be part of the decision making process in this instance prior to the birth of the baby. Parents need the healthcare team to provide information about the baby in a language that is simple and easy to understand. It would be good at this stage to plan where the baby would be born and what the subsequent care will entail after birth.

In cases where the decisions to withhold or withdraw care are made after the baby is born, it is still important for parents and/or family to be considered as partners in all the decision making processes. The decisions as above are made jointly by the healthcare team and the parents/family.

- Immediate care after birth – All babies must be kept dry and warm and comfortable. At this point parents or family members may be given the option to see and hold the baby. It should be noted that some parents or families may choose not to see or hold the baby.

- Medication – There is controversy in the literature regarding the extent to which the following will be provided: inotropic agents, antibiotics, sedation and analgesia, intravenous fluids and enteral feeds. Most authorities would also at this point discontinue electronic monitoring of physiological parameters. For every neonatal unit it would be important to draw up guidelines which would assist the team to make clear and consistent decisions on these matters. There must be avenues within the guidelines for clinical discretion and individualization of care for each and every baby with a balance between clinician responsibility and parental wishes.

- Documentation–All the clinical and ethical decisions made should be documented in the medical records. Ideally these records should be examined at a later stage for all aspects of care, appropriateness of care

and adherence to guidelines. These evaluations should form part of quality of care assessments and opportunities for training.

CHAPTER 6

(Natalie Schellack, Achéle Truter, Zanli van Blerk and Nicolene van der Sandt)

MEDICATION ERRORS IN A NEONATAL INTENSIVE CARE UNIT

6.1 INTRODUCTION

> Medication errors are any preventable event that occurs during any stage of the medication use process that may cause or lead to inappropriate medication use or patient harm. (Clifton-Koeppel: 2008)

Medication errors are any preventable event that occurs during any stage of the medication use process that may cause or lead to inappropriate medication use or patient harm.[190]

Premature babies are susceptible to dosing and dispensing errors due to having a rapid change in body surface area and body weight. Premature babies also have a rapid developing immature system of drug absorption, metabolism and elimination, and an inability to communicate with the provider; and off-label or unlicensed drug usage are often used for these babies.[191]

Premature babies are the most fragile patients in a hospital setting, thus medication errors and adverse effects due to errors are inclined to happen.

Ghaleb *et al*[192] stated that medication dosing for neonates is complicated, reactions to medication is unpredictable and that consequences of medication errors are much more serious in neonatal babies than in adults.[193] But although most medication errors are unlikely to cause serious harm, a small number of

190 Clifton-Koeppel R "What nurses can do right now to reduce medication errors in the neonatal intensive care" (2008) *Newborn and Infant Nursing Reviews* 8(2): 72-82.

191 Jain S *et al* "Medication errors in neonates admitted in intensive care unit and emergency department" (2009) *Indian Journal of Medical Science* 63(4): 146.

192 Ghaleb MA *et al* "The incidence and nature of prescribing and medication administration errors in paediatric inpatients" (2010) *British Medical Journal.*95(2):113–118. http://adc.bmj.com/content/95/2/113. full?sid=a5ec7c8a-96dd-4dfb-bebd-593c89e1b339 [Date of access: 30 Jan. 2014].

193 *Ibid*.

cases are potentially fatal. Therefore, it is important to develop strategies to minimize neonatal medication errors.[194]

A thorough definition for medication errors by The National Coordinating Council for Medication Error Reporting and Prevention is the following: "*A medication error is any preventable event that may cause or lead to inappropriate medication use or patient harm while the medication is in the control of the health care professional, patient, or consumer. Such events may be related to professional practice, health care products, procedures, and systems, including prescribing; order communication; product labelling, packaging, and nomenclature; compounding; dispensing; distribution; administration; education; monitoring; and use*."[195]

It is important to realize that a medication error can occur in any way by anyone in a hospital setting and that when searching for errors all the health care professionals responsible for the patients' caregiving should be included.

6.2 RISK FACTORS ASSOCIATED WITH MEDICATION ERRORS IN A NEONATAL INTENSIVE CARE UNIT (NICU)

Risk factors associated with medication errors in the NICU can be related to patient factors, medication factors and the environment within the intensive care unit as evidenced by the data displayed in Table 6.1 below.[196]

Table 6.11: The risk factors associated with medication errors in a neonatal intensive care unit.

Risk Factor:	Comment:
Patient factors	• Gestational age–based physiologic immaturity of liver, kidneys, cardiovascular system • Fragile population increasing risk of serious effects of medication errors

194 Clifton-Koeppel R (2008) 72-82.
195 National Coordinating Council for Medication Error Reporting and Prevention, NCCMERP, 2014 http://www.nccmerp.org/ [accessed on 28 January 2014].
196 Clifton-Koeppel R (2008) 72-82.

	· Increased length of stay, need for complex treatments · Weight-based dosing requirements · Nonverbal patient, increased incidence of multiple births, frequent relocation of infant, and identification bands are too big (increasing risk of patient identification errors)
Medications	· Off-label use common · Adult strength doses often diluted before dispensing and/or administration
Intensive care environment	· High-risk environment · Often crowded, multiple personnel, and equipment

(Adapted from a study on: "What nurses can do right now to reduce medication errors in the neonatal intensive care unit" by Clifton-Koeppel).[197]

6.3 CLASSIFICATION OF MEDICATION ERRORS

A variety of different studies found a wide array of different types of medication errors that occur in a hospital setting. The origin of the error is important due to knowing and finding out where the primary problem of the medication error is, and into what type of error it resulted. If the primary problem is known, strategies can be implemented to announce and then reduce these medication errors.

Jhanjee *et* al[198] verifies that these are the **five stages** of the medication process where medication errors can occur and that most medication errors occur as a result of multiple, compounding events rather than from a single individual:

a) Ordering/prescribing: A Process involving the action to issue a medication order by a legitimate prescriber in writing.

b) Transcribing and verifying: Documentation of an order by someone other than the prescriber for ordering processing.

c) Dispensing and delivering: Process of a pharmacist assessing a medication order and releases the product for use by another health care professional.

d) Administering: Process where the medication and patient interface followed by documentation and monitoring. Actual administration of medication to

197 *Ibid*.

198 Jhanjee A *et al* "Medication errors in clinical practice" (2011) *Delhi Psychiatry Journal* 14(2):205-210; Lerner RB *et al* "Medication errors in a neonatal intensive care unit" (2008) *Jornal de Pediatria* 84(4): 166-170.

the patient which includes giving the right medication to the right patient at the right time.

e) Monitoring and reporting: Evaluating the patient's response to the medication and to record the findings.

In a study on medication errors in neonates admitted to NICU and emergency departments, researchers were also looking at other studies and conducted their own research; they came to the conclusion that the most error-prone step in the medication process is due to ordering by the prescriber. Dosing errors are the leading cause of medication errors, especially in the paediatric population. Results of these errors vary from 14% to 82%.[199]

Types of medication errors found by several studies:[200]

- Wrong medicine – patient receives a medication which the physician did not order or the medication is contraindicated, a duplication or inappropriate for the patient.
- Wrong dose – total daily dose, dose according to weight per kilogam, using milligrams instead of micrograms, and the dose could be too low/high or dosage regime not too frequent and a patient receiving an amount greater or less than the amount ordered.
- Wrong preparation – product incorrectly prepared or manipulated before administration, medication then given in the wrong concentration, in the wrong fluid, or at the wrong rate and using the wrong technique.
- Wrong time – patient receive medication out with the prescribed time frame (wrong frequency), duration of treatment too long/short.

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199 Jain S *et al* "Medication errors in neonates admitted in intensive care unit and emergency department." (2009) *Indian Journal of Medical Sciences* 63(4):145-151.

200 Adapted from: Jhanjee A *et al* "Medication errors in clinical practice" (2011) *Delhi Psychiatry Journal* 14(2):205-210; Khalil H *et al* "Role of clinical pharmacists' interventions in detection and prevention of medication errors in a medical ward" (2011) *International Journal of Clinical Pharmacy and Pharmaceutical Care* 33:281–284; Otero P *et al* "Medication errors in pediatric inpatients: Prevalence and results of a prevention programme" (2008) *Journal of the American Academy of Pediatrics* 22(3): 737-743; Ross LM *et al* "Medication errors in a paediatric teaching hospital in the UK: Five years operational experience" (2000) *BMJ* 83(6): 492-497; Wong ICK *et al* "Minimising medication errors in children" (2008) *Archives of Disease in Childhood* 94(2):161–164.

- Wrong route – correct dosage form administered in the incorrect site of the body.
- Unauthorised – medication that is given to the patient that was not prescribed by the physician, no clear indication for medication usage is stated or there could be a clear indication for medication use but not prescribed.
- Omission – medicine prescribed but not given at the time the next dose is due, omission of a written prescription (verbal orders), omission of time administrated drug was prescribed, omission of medication administrated but not stated that it was suspended.
- Wrong patient – medication prescribed, dispensed or administrated to the wrong patient.
- Wrong labelling – not labelled according to the prescription, resulting in wrong patient, wrong dose, wrong route, etc.
- Wrong dispensing – wrong drug, wrong strength, wrong route, wrong amount dispensed by the pharmacy.
- Miscalculation – individualised dose for patient not calculated correctly based on the patient's age, degree of prematurity, weight and clinical condition.
- Extra dose error: patient receives more dosage units than prescribed or receiving a dose after it was cancelled.
- Deteriorated drug error: physical or chemical integrity of medication dosage has been compromised, expired medication or medications requiring refrigeration.

6.4 CAUSES OF MEDICATION ERRORS

The causes of medication errors in general clinical practice can be divided into human- and system errors.

Human errors consist of performance deficit, procedure or protocol not followed, miscommunication, inaccurate or omitted transcription, improper documentation, knowledge deficit, miscalculation, missing or misplaced zero and decimal points,

use of non standard abbreviations, lack of patient information and lack of patient understanding of their therapy.[201] Human errors are compounded when wards are overcrowded as it leads to an increase in workload, generating more stress, tiredness and sleep deprivation in the healthcare professional, facilitating the occurrence of more medication errors.[202]

Factors that contribute to **system errors** include medications with similar names, complex or poorly designed technology, access to medication by non-pharmacy personnel, drug distribution system errors, computer entry error, lack of system safeguards, and workplace environmental problems that include the daily occupancy rate and the workload of the healthcare professionals.[203]

6.5 THE ROLE OF THE CLINICAL PHARMACIST IN MEDICATION ERRORS

The importance of the clinical pharmacist working with neonates in monitoring their drug treatment and preventing medication errors is well established. The medication process is related to improvement due to a clinical pharmacist working in collaboration with physicians and nurses on medication activities. Pharmaceutical care provided by clinical pharmacists in the hospital allows a multiple layer of patient protection, which can reduce the potential risks of medication errors.[204]

According to Simpson *et al*[205] clinical pharmacists that monitor medication orders might prevent 58% of all errors and 72% of potentially harmful errors, and that improved doctor-pharmacist communication might prevent 47.4% of errors.
In another inpatient paediatric medication errors study, it is estimated that 81% of errors could have been avoided with pharmacist monitoring the patients and that

201 Jhanjee A *et al* (2011):205-210.
202 *Ibid*.
203 *Ibid*.
204 Khalili H *et al* "Role of clinical pharmacists' interventions in detection and prevention of medication errors in a medical ward" (2011) *International Journal of Clinical Pharmacy and Pharmaceutical Care*, 33(2):281–284.
205 Simpson JH *et al* "Reducing medication errors in the neonatal intensive care unit" (2004) *BMJ* 89(6):480-482.

47% could have been avoided by improving communication between physicians and pharmacists.[206]

Daily responsibilities of a Clinical pharmacist:

- ✓ Review the patients' medical charts.
- ✓ Patient therapeutic drug monitoring.
- ✓ Complete the patient's pharmacotherapy monitoring form.
- ✓ Attend medical ward rounds.
- ✓ Report related drug therapy problems to the physician in charge.
- ✓ Educate health care professionals about drug therapy.[207]

As stated before medication errors occur frequently in hospital wards. A clinical pharmacist can effectively prevent and reduce medication errors through implementing interventions and continuous education to health care professionals. According to Clifton-Koeppel[208] if common medication errors are unknown in the hospital wards, learning and implementation of error prevention strategies cannot be implemented. It is important to alert all health care professionals that medication errors are common and very frequent.

Thus, according to Wong *et al*,[209] there is sufficient evidence to recommend clinical pharmacist services in hospital wards. Especially ward-based prescription monitoring that will improve communication between health care professionals and to educate and train health care professionals in the use of medicines.

206 Wong ICK *et al* "Minimising medication errors in children" (2008) *Archives of Disease in Childhood*, 94(2):161–164.

207 Khalili H *et al* "Role of clinical pharmacists' interventions in detection and prevention of medication errors in a medical ward" (2011) *International Journal of Clinical Pharmacy and Pharmaceutical Care* 33(2):281–284.

208 Clifton-Koeppel R (2008) (2008) 72-82.

209 Wong ICK *et al* (2008) 161–164.

6.6 THE ROLE OF THE CLINICAL PHARMACIST IN A NEONATAL INTENSIVE CARE UNIT

A study done on the effect of educational strategy to reduce medication errors in a neonatal intensive care unit established that it is of high importance to have a clinical pharmacist at bedside of neonatal babies in NICU.[210]

Role of a clinical pharmacist in NICU

- Pharmaceutical care to NICU patients.
- Pharmacokinetic monitoring.
- Drug distribution support.
- Up-to-date information on reconstitution and dilution of drugs.
- Compatibility of intravenous medications.
- Clinical interventions.
- Multidisciplinary group participation.
- Investigational drug studies.
- Research.
- Teaching and pharmacy representation on paediatric committees.[211]

Thus it should be accentuated that individualised dose regimes are required for NICU patients and very careful monitoring to reduce medication errors.

210 Campino A *et al* "Educational strategy to reduce medication errors in a neonatal intensive care unit" (2009) *Acta Paediatrica,* 98(5):782-785.

211 *Ibid*.

SECTION C

DECISION-MAKING: POST-DISCHARGE AND THERAPEUTIC SUPPORT

CHAPTER 7

(Emmaré Stronkhorst)

SUPPORT AFTER HOSPITAL DISCHARGE

7.1 INTRODUCTION

In this chapter we aim to provide information on the needs of parents when their infant with complex health needs is discharged from neonatal intensive care unit (NICU) and should be cared for at home. We also provide guidelines on specific situations to improve the discharge planning and transition to home. When parents take care of their infant with complex health needs at home it is not done in isolation and they will need support from within their community[212] and broader resource systems. Literature has discussed the importance of supporting these parents,[213] as this has a big impact on the well-being of the parents as well as the child.

7.2 PREPARING FOR DISCHARGE

Having an infant in a neonatal intensive care unit (NICU) increases anxiety and stress which may still last for up to 2 years after the infant has been born.[214] "Infants born preterm with low birth weight who require neonatal intensive care experience a much higher rate of hospital readmission and death during the first year after birth compared with healthy term infants. Careful preparation for

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212 Kirk S "Families' experiences of caring at home for a technology-dependent child: a review of the literature" (1998) *Child: Care, Health and Development* 24(2):103; Marlow N *et al* "Neurologic and developmental disability at six years of age after extremely preterm birth" (2005) *New England Journal of Medicine* 352(1):11-13; Riley K *et al* "Survival and neurodevelopmental morbidity at 1 year of age following extremely preterm delivery over a 20-year period: a single centre cohort study" (2008) *Acta Pædiatrica* 97(2):163.

213 Dunst CJ "Revisiting 'rethinking early intervention'" (2000) *Topics in early childhood special education,* 20(2):99; Farmer JE *et al* "Primary care supports for children with chronic health conditions: identifying and predicting unmet family needs" (2004) *Journal of Pediatric Psychology* 29(5):362; Johnston BD *et al* "Expanding developmental and behavioral services for newborns in primary care: effects on parental well being, practice, and satisfaction" (2004) *American Journal of Preventive Medicine* 26(4):360, 362; Van der Walt K *Resilience in Families with an Autistic Child* (University of Stellenbosch.Unpublished Dissertation – MA (2006)) 103-104.

214 Bakewell-Sachs S and Gennaro S "Parenting the post-NICU premature infant" (2004) *American Journal of Maternal/Child Nursing* 29(6):399.

discharge and good follow-up after discharge may reduce these risks."[215] Discharge planning should begin early and different components should be included in the planning to facilitate successful transition to home care.

7.2.1 Parental education is central in helping parents to move from the medicalised NICU setting to an individualised home setting. Education pre-discharge may include teaching on infant cues and how to respond to them, infant development and behaviour, infant stimulation, feeding, engaging with the infant, how to use equipment used in the care of the infant, mastering normal daily tasks like bathing and positioning the infant and developmentally based care.[216] One of the main concerns parents have are feeding of the infant and their preparedness to do it correctly. Other concerns related to discharge as identified through a literature review include development of the infant, management of the infant at home and emotional support.

7.2.2 How discharge teaching is delivered is a predictor of parental readiness for hospital discharge and is influenced by the nurses' skill to individualise learning according to the parents' needs and style.[217] Therefore discharge teaching should be taken seriously, be planned and not rushed. Parents may also need some help to envision what information they will need to cope with their child post-discharge to prevent them from discarding important information as being unnecessary.[218] Providing information on their primary health care provider after discharge and resources available should be part of discharge planning.

7.2.3 Preparing the infant for discharge should include screening, feeding, weighing and immunisations of the infant. Screening of vision and

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215 American Academy of Pediatrics "Hospital discharge of the high-risk neonate" (2008) *Pediatrics* 122(5):1119-1126.

216 Bakewell-Sachs S and Gennaro S (2004) 400.

217 Weiss M *et al* "Readiness for discharge in parents of hospitalized children" (2008) *Journal of Pediatric Nursing* 23(4):282-295.

218 *Ibid*.

hearing should preferably be done on all qualifying infants before discharge from the NICU. There is a high prevalence of anaemia after neonatal intensive care and assessment of haematological status is recommended.[219] Premature infants usually require iron supplementation for the first year of life.[220]

7.2.4 The nutritional status of the infant can be seen in the measurement of weight, height and head circumference and development. Proper follow-up care and well-baby check-ups are therefore very important. Late preterm infants who are breastfed and discharged early has an increased risk of neonatal morbidity and should be followed-up more closely.[221] Good and correct breastfeeding education is important for successful and sustained breastfeeding post-discharge.[222]

7.2.5 Immunisations are a critical part of preventative care and vaccination of the premature infant should still be administered according to the infant's chronological age, with the exception of Hepatitis B in infants weighing less than 2000g.[223] Respiratory syncytial virus (RSV) is a common cause of bronchilitis and pneumonia in infants and vaccination against RSV should be done as indicated. LaHood and Bryant[224] strongly suggest influenza vaccination for infants older than six months or for the family members and close contact of infants younger than six months.

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219 American Academy of Pediatrics (2008) 1122.

220 LaHood A and Bryant C "Outpatient care of the premature infant" (2007) *American Family Physician* 76(8) 1162.

221 Tomashek KM *et al* "Early discharge among late preterm and term newborns and risk of neonatal morbidity" (2006) *Seminars in Perinatology* 30(2):66.

222 For feeding and nutrional recommendations, see chapter 8 below.

223 LaHood A and Bryant CA (2007) 1160.

224 *Idem* 1159-1164.

7.3 BONDING AND ATTACHMENT

Attachment is mainly influenced by the role parents play in shaping the relationship with their infant and parental sensitivity influences the attachment behaviour of the child.

7.3.1 Sensitivity of the parents to their infant's needs largely depends on parents' ability to recognise and understand a child's behaviour, body language, speech and facial expressions.[225] Infants and children with complex health needs may have delayed ability to show attachment related behaviour like smiling, vocalisations or approaching and the clarity of their communication may be impaired by their disability. Their caregivers may therefore have difficulty reading their cues and easily feel as if the infant or child does not want to interact with them. Parents may feel that their infants are not interactive and therefore become less sensitive to their infant's needs. This can further increase parental stress and influence the parent's behaviour towards her infant.[226] Infants and children who feel misunderstood, unrecognised and ignored become distressed and amplify their attachment behaviour, which in turn increases stress and frustration in the parent.[227] These difficulties may make it more likely for children with complex health needs to have insecure attachments.

Parents' sensitivity is also influenced by their economic status, own attachment issues and unresolved feeling towards child's diagnosis. The more vulnerable parent will find the attachment needs of their disabled child stressful. Parents with strained economical, social and psychological resources will find challenging children as an extra stressor and these children will more likely be classified as insecure

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225 Howe D "Disabled children, parent-child interaction and attachment" (2006) *Child & Family Social Work* 11(2):97.

226 Howe D (2006) 11(2):99; Malekpour M "Effects of attachment on early and later development" (2007) *The British Journal of Developmental Disabilities* 53:88-89.

227 Howe D (2006) 11(2):99.

attached.[228] Howe[229] states how ironic it is that children with complex health needs especially need sensitive parenting, but challenge their parents' ability to provide such care.

7.3.2 Secure attachment positively influences brain development,[230] emotional and psychological well-being and physical development. Healthy parent-child attachment leads to positive impacts which have long-term effects on a child's developmental outcomes.[231] Malekpour[232] suggests strategies to help form secure attachments like physical contact together with stimulation of the infant, eye contact, smiling, talking and being responsive to the infant's needs. Mothers can be supported by providing positive social interactions with their disabled children. Howe[233] suggests the following support to help prevent insecure attachments for the at-risk "mother-disabled child" dyad: encourage good social support, provide clear and understandable information on the child's disability and how it will effect communication, help parents to resolve issues of loss and trauma and help insecure parents with their own attachment issues. This relates closely to what parents of infants with complex health needs identified as their support needs in South Africa.[234] Infants with complex health needs are often separated from their mothers and having a child with complex health needs may complicate the infant-mother dyad, therefore professionals should encourage bonding and advise parents on strategies to enhance bonding and attachment like babywearing and infant massage.

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228 *Idem* 95.

229 *Idem* 99.

230 Malekpour M "Effects of attachment on early and later development" (2007) *The British Journal of Developmental Disabilities* 53:84.

231 Malekpour M (2007) 92.

232 *Idem* 90.

233 Howe D (2006) 103.

234 Stronkhorst JE *Exploring the Support Needs of Parents of Infants with Complex Health Needs in the Community (*North-West University (2012) Unpublished Dissertation – MCur) 53.

7.3.3 Babywearing has many benefits and may be beneficial to the infant with complex health needs as it stimulates and support secure attachment, reduces infant crying, stimulates the vestibular system and may enhance speech development.[235] Babywearing calms the infant and teaches the infant to be content while providing a stimulating environment as the caregiver moves around with the infant. A calm infant is able to receive more stimulation and learn more as he spends more time in a quiet alert state. Babywearing also fosters a more attentive caregiver as the infant is always in close contact with the caregiver and his needs can be met promptly. This again supports the development of a secure attachment.

7.3.4 Infant massage empowers parents to connect with their infant and teach them how to read and understand their infant's non-verbal language and cues, therefore helping them to respond to their infant with respect and love. Infant massage is the slow, rhythmic and deep massage of an infant's body by his/her caregiver (not a stranger), thereby creating optimal skin stimulation for the infant.

One of the main benefits of infant massage is that it promotes bonding and secure attachment as touch is a fundamental part of bonding. Apart from the positive effect on bonding, infant massage has many other benefits. It can be categorised into four general benefits: interaction, stimulation, relief and relaxation.[236] These include benefits like improved self-esteem and self-image, feeling respected, stimulation of the digestive system and immune system, improved circulation, relieving of gas, cramps and constipation, helping with teething problems, relief of stress, improved sleep

235 Sears W and Sears M *The Attachment Parenting Book: A Commonsense Guide to Understanding and Nurturing your Baby* (2001) *Little, Brown* 68-77.

236 McClure VS *Teaching Infant Massage: A Handbook for Instructors. International Association of Infant Massage* (2005) 32.

patterns, improved weight gain, increased flexibility, lowering of stress hormones and many more.[237]

7.3.5 Different elements help to promote bonding between an infant and a parent. Keeping these elements in mind is important when encouraging bonding between a child and a parent and will help parents to realise that bonding is possible through different ways and that they should not be discouraged if one or more elements are not possible to use. The elements are touch, eye contact, odour, hearing and speaking, crying, smiling, nursing or feeding, imitation and biorhythm.[238]

7.3.6 The benefits and importance of skin-to-skin contact is overwhelming and far reaching.[239]

7.4 PARENTAL SUPPORT NEEDS IN THE COMMUNITY

Parents of infants with complex health needs experience many stressors, including facing challenges in their daily lives, emotional well-being, physical environment, financial well-being, social well-being, obtainment of skills and their contact with services and professionals.[240]

Six main parental support needs were identified in South Africa,[241] regardless of the socio-economic background of the parent:

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237 To view research articles on infant and child massage see Touch Research Institute (http://www6.miami.edu/touch-research/).
For more information on the International Association of Infant Massage see www.iaimsa.co.za and www.iaim.net.

238 McClure VS T*eaching Infant Massage: A Handbook for Instructors. International Association of Infant Massage* (1998) 39.

239 It is too vast to describe in this document, but further reading can be done at http://skintoskincontact.com.

240 Abbott D *et al* "The proof of the pudding: what difference does multi-agency working make to families with disabled children with complex health care needs?" (2005) *Child and Family Social Work* 10(3):231.

241 Stronkhorst JE (2012) 103.

- The need for information
- The need for parent-to-parent support
- The need for professional support
- The need for self-confidence in the care of the infant
- The need for social support
- The need for normality.

Knowing and understanding these needs can improve support and service delivery to parents of infant with complex health needs.

7.4.1 *The need for information.* The need for information includes types of information needed and the communication of this information. It is important to provide educational information like what to do in an emergency situation, how the child's condition influences his or her development and the effects and side-effects of medication. Practical information and advice on how to access available equipment, home care, daily care giving and what the future holds should also be provided.[242] Information on resources and support available in the

[242] Aytch LS *et al* "Seizures in infants and young children: an exploratory study of family experiences and needs for information and support" (2001) *Journal of Neuroscience Nursing* 33(5):282; Bailey DB *et al* "Needs expressed by mothers and fathers of young children with disabilities" (1992) *American Journal of Mental Retardation* 97(1):5; Diehl SF *et al* "Focus group interview with parents of children with medically complex needs: an intimate look at their perceptions and feelings" (1991) *Children's Health* Care 20(3): 173, 177; Kerr SM and McIntosh JB "Coping when a child has a disability: exploring the impact of parent-to-parent support" (2000) *Child: Care, Health and Development* 26(4):314; Kirk S and Glendinning C "Supporting 'expert' parents: professional support and families caring for a child with complex health care needs in the community" (2002) *International Journal of Nursing Studies* 39(6):632; McPhee KB *The Perceived Needs of Maine Parents of Premature Children for Services and Supports: A Retrospective Longitudinal Study"* (Maine: University of Maine. Unpublished Thesis – PhD) (2010) 80; Molinari DL and Freeborn D "Social support needs of families adopting special needs children" (2006) *Journal of Psychosocial Nursing and Mental Health Services*, 44(4):32; Moola HH *The Life-world of Indian Parents' with a Down's Syndrome Child* (Durban: University of Zululand. Unpublished Dissertation - MEd) (1996) 132, 183; Newton A *Differences in Stress and Needs Identified by Mothers of Young Children with Developmental Disabilities at Point of Entry into the Service System* (Winnipeg: University of Manitoba. Unpublished Thesis – MSocSc) (2006) 40; Pelchat D *et al* "Parental satisfaction with an early family intervention program" (2004) *Journal of Perinatal & Neonatal Nursing* 18(2):134; Tong A *et al* "Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study" (2010) *Child: Care, Health and Development* 36(4):555; Young LY, Creighton DE and Sauve RS "The needs of families of infants discharged home with continuous oxygen therapy" (1988) *Journal of Obstetric, Gynecologic and Neonatal Nursing,* 17(3):189.

community and how to access them is very important to parents.[243] Ensure that the information provided is accurate, up-to-date and relevant and if possible in written form in order for parents to refer back to it and share it with family members and caregivers.[244] Parents also mentioned that they would like to receive information at an early stage after diagnosis of the child.

7.4.2 *The need for parent-to-parent support.* Parents in similar situations have a perceived sameness that makes it easier to relate, share emotions and experiences and give support. Contact with other parents creates awareness that they are not alone in this situation, and this provides comfort and reassurance.[245] Support can be offered in the form of support groups or individual conversations.

7.4.3 *The need for professional support.* Professional support includes a variety of support. First, parents indicated that they need counselling and this service should be offered.[246] Parents often struggle with feelings of isolation, guilt and anxiety and need help in responding to neighbours and friends. Secondly, a service coordinator is important in linking services, ensuring continuity of care, being an advocate for the family and being available for and familiar with the family and their circumstances.[247] Thirdly, parents of infants with complex health

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243 Aytch LS *et al* (2001) 282; Bailey DB *et al* (1992) 5; Diehl SF *et al* (1991):173; Kirk S and Glendinning C (2002) 632; Molinari DL and Freeborn D (2006) 32; Moola HH (1996) 139; Pelchat D *et al* (2004) 134; Stronkhorst JE (2012) 81; Tong A *et al* (2010) 555.

244 Aytch LS *et al* (2001) 282; Bailey DB *et al* (1992) 5; Diehl SF *et al* (1991) 173; Kerr SM and McIntosh JB (2000) 314; Muggli EE *et al* "Going down a different road: First support and information needs of families with a baby with Down syndrome" (2009) *Medical Journal of Australia* 190(2):59; Kirk S and Glendinning C (2002) 632; Pelchat D *et al* (2004) 137; Tong A *et al* (2010) 553, 555.

245 Kerr SM and McIntosh JB (2000) 317; Konrad SC "What parents of seriously ill children value: parent-to-parent connection and mentorship" (2007) *Omega* 55(2):121; Stronkhorst JE (2012) 84.

246 Kirk S and Glendinning C (2002) 629; Moola HH (1996) 152; Newton A *Differences in Stress and Needs Identified by Mothers of Young Children with Developmental Disabilities at Point of Entry into the Service System* (Winnipeg: University of Manitoba. Unpublished Thesis – MSocSc) (2006) 40; Pelchat D *et al* (2004) 133; Stronkhorst JE (2012) 87; Tong A *et al* (2010) 553, 555.

247 Diehl SF *et al* (1991) 173-174; Kirk S and Glendinning C (2002) 625-635; Molinari DL and Freeborn D (2006) 31; Muggli EE *et al* (2009) 59; Stronkhorst JE (2012) 88; Young LY *et al* (1988) 189.

needs have the need for accessible, knowledgeable professionals[248] and professionals who will be honest with them about their child's condition and care.[249] It is therefore important to refer to the correct professionals. Lastly, parents expressed the need for professional services including quality health care, childcare, respite care and developmental services.[250] Parents emphasised the need for child care for their infant and mostly rely on family members to look after their infant.[251] This can put extra strain on their social support system.

7.4.4 *The need for self-confidence in the care of the infant.* As parents are the main caregivers of infants with complex health needs they need to gain self-confidence in the care of the infant. They can be supported psychologically through being well-informed, becoming an advocate for their child, encouragement, positive feedback and being included in the decision-making process.[252] Practical support will include teaching them procedures at home and hands-on training on equipment use.[253]

7.4.5 *The need for social support.* Social support includes support from family, friends and the community. Relatives, friends and the church community are important sources of support[254] and it is important to remember that spousal support is seen as the most helpful.[255] Community support can be offered in the form of resources, associations and support groups, for example Down Syndrome South Africa. The availability of social support is essential for the

248 Aytch LS *et al* (2001) 282; Kerr SM and McIntosh JB (2000) 316; Kirk S and Glendinning C (2002) 632.

249 Kirk S and Glendinning C (2002) 628; Konrad SC (2007) 122; Tong, A *et al* (2010) 551.

250 Aytch LS *et al* (2001) 282; Diehl SF *et al* (1991) 172; McPhee KB (2010) 78, 82; Molinari DL and Freeborn D (2006) 30; Tong A *et al* (2010) 551; Young LY *et al* (1988) 190.

251 Stronkhorst JE (2012) 90.

252 Diehl SF *et al* (1991) 174; Kirk S and Glendinning C (2002) 39(6) 628, 632; Konrad SC "What parents of seriously ill children value: parent-to-parent connection and mentorship" (2007).*Omega* 55(2) 124; Molinari DL and Freeborn D (2006) 32; Pelchat D *et al* (2004) 136.

253 Diehl SF *et al* (1991) 174; Kirk S and Glendinning C (2002) 632; Young LY *et al* (1988) 189.

254 Aytch LS *et al* (2001) 282; Moola HH (1996) 145-146; Muggli EE *et al* (2009) 59; Pelchat D *et al* (2004) 137; Tong A *et al* (2010) 555; Young LY *et al* (1988) 17(3)190.

255 Stronkhorst JE (2012) 5; Young LY *et al* (1988) 190.

successful adaptation of a parent to home-care of his/her infant with complex health needs. Increased support from a mother's partner and informal network reduces negative attitudes toward her child.[256]

7.4.6 *The need for normality.* Parents of infants with complex health needs have the need for their children to feel and be treated normal. They want their infants to grow up with confidence. It is important for them to recognise what is normal in the infant and not only focus on the abnormalities or complex health needs.[257] Normality is therefore emphasised[258] and the disability described as insignificant. Focussing on what is normal and making parents aware of those aspects will provide extra support to parents of infants with complex health needs.

7.5 SPECIFIC SITUATIONS AFTER DISCHARGE

Deciding to discharge an infant from NICU can be complex and is based on the medical condition of the infant and the parents' readiness to take the infant home. The parents should feel confident in giving the extra support the infant may need at home. The main supportive technologies newborns with complex health needs require after discharge are nutritional and respiratory support.[259] The following are guidelines in specific situations to help with discharge.

256 McCurdy K "The influence of support and stress on maternal attitudes" (2005). *Child Abuse and Neglec* 29(3) 261.

257 Stronkhorst JE (2012) 98.

258 Broberg M "Expectations of and reactions to disability and normality experienced by parents of children with intellectual disability in Sweden" (2011) *Child: Care, Health and Development* 37(3) 412.

259 American Academy of Pediatrics "Hospital discharge of the high-risk neonate" (2008) *Pediatrics* 122(5) 1120.

7.5.1 Weight and feeding of the infant discharged form NICU

Early nutritional support of the preterm infant influences their long-term health outcomes and development, therefore monitoring of their weight and growth are just as important post-discharge as in hospital. Deciding on the correct nutrition for low birth weight infants should be individualised and monitored by a specialist.[260]

The late preterm infant is at risk for poor lactation and breastfeeding should be closely monitored to ensure proper latching, sufficient milk removal, milk production and weight gain. In order to support breastfeeding in the late preterm, it is important to establish the mother's milk supply and ensure that the infant is adequately fed.[261]

7.5.2 Oxygen dependant infants discharged from NICU

Long term oxygen therapy may be required throughout the day or only during periods of sleep. A child requiring oxygen therapy for more than 2-3 weeks should be considered for discharge on home oxygen therapy.[262] Discharging an infant on oxygen therapy may achieve earlier hospital discharge. The following should be considered when discharging an infant or child on home oxygen therapy:

- Facility-specific discharge criteria can be set. This allows for a discharge plan to be followed and the multi-disciplinary team to prepare the infant for discharge.
- Infant will be discharged on a prescribed amount of oxygen.
- The family doctor, paediatrician or clinic sister should be informed of the infant's discharge, thereby mobilising community support.
- At home oxygen saturation should be monitored as prescribed and not unnecessarily be measured continuously as this may lead to excessive adjustment of the oxygen flow by the caregivers.[263]

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260 For more information on feeding and nutrition refer to Dietetic section. See par 3.2 below.

261 Meier PP *et al* "Increased lactation risk for late preterm infants and mothers: evidence and management strategies to protect breastfeeding" (2007) *Journal of Midwifery and Women's Health* 52(6) 582.

262 Balfour-Lynn IM *et al* "Home oxygen for children: who, how and when?" (2005) *Thorax* 60(1) 76.

263 *Idem* 79.

- The infant's vital signs, feeding and weight should also be monitored at prescribed intervals by a health care professional.
- A plan for weaning off oxygen should be in place, with support and supervision of a health care professional.
- Educate parents on what to do in an emergency situation.
- Follow-up visit/s should be scheduled before discharge.
- Equipment to organise before discharge as needed: home oxygen, oxygen saturation monitor, ambulatory oxygen, apnoea sensor and alarm (if indicated).
- If the family lives far from the hospital consider organising ambulance transport for the infant in order for the infant to be monitored as needed.
- Parents should be willing to and feel capable of taking the infant home on oxygen therapy.
- Parents should be trained to care for the infant on oxygen therapy at home.
- Advice should be given on no smoking in the home and open flames near the oxygen.

7.5.3 Infant discharged from NICU requiring nasogastric feeds

Nasogastric or gastrostomy feedings are usually given to compliment oral feeds to ensure adequate total intake.

- Facility-specific discharge criteria can be set. This allows for a discharge plan to be followed and the multi-disciplinary team to prepare the infant for discharge.
- Infant will be discharged on a prescribed amount of feeds.
- Caregivers should be confident in administration nasogastric feeds before discharge of the infant. Not all caregivers are capable of safely giving nasogastric feedings and should therefore be assessed before discharging the infant.
- The type, size, length of insertion and who confirmed the correct position of the nasogastric tube should be recorded and marked thoroughly in order to prevent potential complications.

- Educate caregivers on what to do in an emergency situation and when to suspect tube misplacement and therefore not to use the nasogastric tube before it is checked.
- Follow-up visit/s should be scheduled before discharge for weight monitoring and change of nasogastric tube.
- Develop a facility-specific nasogastric tube changing chart to record the change of the nasogastric tube, the placement, length and position tested.

7.5.4 Infant discharged from NICU with a tracheostomy

- Facility-specific discharge criteria can be set. This allows for a discharge plan to be followed and the multi-disciplinary team to prepare the infant for discharge.
- Caregiver education should be done in a non-threatening manner to achieve preparedness and confidence for discharge.
- Educational topics may include: airway management, tracheostomy care, cardiopulmonary resuscitation, manual ventilation, suctioning, use and administration of oxygen, pulse oximetry, chest physical therapy and ventilator (if indicated).[264]
- Caregivers should have a contact person to contact in case of an emergency or if in doubt.
- Home ventilation usually requires qualified personnel and home-nursing should be considered.
- Home visits may provide additional support, education to the caregiver and monitoring of the infant.
- Good coordinated multidisciplinary follow-up care is essential.[265]

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264 Tearl DK and Hertzog JH "Home discharge of technology-dependent children: evaluation of a respiratory-therapist driven family education program" *Respiratory Care* 52(2) 173.

265 American Academy of Pediatrics "Hospital discharge of the high-risk neonate" (2008) *Pediatrics* 122(5) 1121.

7.6 AVAILABILITY OF RESOURCES

It is well-recorded that parents of children with complex health needs report inadequate information on services available, although they have the need for this information.[266]

Unfortunately, this is often related to few services available.[267] In South Africa parents find the availability of services a challenge as there is a lack of services and support.[268] Few services and poor referral and follow-up after screening may lead to delayed diagnosis of the infant with complex health needs.[269] Extensive travelling to clinics, the cost of health care, waiting periods to receive services, inappropriateness of services and delayed diagnosis of the child have been reported as barriers to accessing services.[270]

South African guidelines proposed for the management of the developmental needs of infants are family-centred care, developmental care of infants as central focus, establishing resources and infrastructure, professional management and

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266 Buran CF *et al* Sawin K, Grayson P and Criss S "Family needs assessment in a cerebral palsy clinic" (2009) *Journal for Specialists in Pediatric Nursing* 14(2) 89; Minnes P and Steiner K "Parent views on enhancing the quality of health care for their children with fragile X syndrome, autism or Down syndrome" (2009) *Child: Care, Health and Development,* 35(2) 252; Sloper P and Turner S "Service needs of families of children with severe physical disability" (1992) *Child: Care, Health and Development* 18(5) 271; Wood DL *et al* "A multi-method assessment of satisfaction with services in the medical home by parents of children and youth with special health care needs" (2009) *Maternal Child Health Journal* 13(1) 13.

267 Abbott D *et al* "The proof of the pudding: what difference does multi-agency working make to families with disabled children with complex health care needs?" (2005) *Child and Family Social Work* 10(3) 234; Hemming E and Akhurst J "Mothers' life-worlds in a developing context when a child has special needs" (2009) *Indo-Pacific Journal of Phenomenology* 9(1); Wood, D.L *et al* (2009) 13(1) 13.

268 Hemming E and Akhurst J (2009) 9(1).

269 Lloyd G "The importance of early intervention" http://www.downsyndrome.org.za/main.aspx?artid=66 [Date of access: 8 July 2012]; Swanepoel D *et al* "Early hearing detection and intervention in South Africa" (2009) *International Journal of Pediatric Otorhinolaryngology* 73(6) 785; Van der Spuy T and Pottas L "Infant hearing loss in South Africa: age of intervention and parental needs for support" (2008) *International Journal of Audiology* 47(Suppl.1) S32.

270 Buran CF *et al* "Family needs assessment in a cerebral palsy clinic" (2009) *Journal for Specialists in Pediatric Nursing* 14(2) 91; Hemming E and Akhurst J (2009) 9(1); Minnes P and Steiner K "Parent views on enhancing the quality of health care for their children with fragile X syndrome, autism or Down syndrome" (2009) *Child: Care, Health and Development* 35(2) 2.

effective management of infants with developmental delays and disabilities.[271] These guidelines are important as Bornman and Alant[272] reported that in rural areas of South Africa referral of these infants are inadequate and compliance to referral low. Transport problems and financial difficulties of the caregivers are largely known to contribute to this problem.

7.7 CONCLUSION

Parents have many challenges caring for their infant or child with complex health needs at home. Providing proper discharge planning and post-discharge support have a positive impact on the well-being of the parent, parent-child relationship and the child. Even with poor availability of resources health care professionals can still provide good support through proper referral and follow-up care as a multidisciplinary team.

271 Leech R *et al* "The management of infant developmental needs by community nurses. Part 2: the development of guidelines for the support of community nurses in themanagement of infant developmental needs" (2007) *Curationis* 30(2) 107.

272 Bornman J and Alant E "Community nurses' perceptions of and exposure to children with severe disabilities and their primary caregivers" (2002) *Health SA Gesondheid* 7(3) 46.

CHAPTER 8

(Francine Coetzee)

GUIDELINES FOR FEEDING CRITICALLY ILL CHILDREN IN THE PAEDIATRIC INTENSIVE CARE UNIT AND THE NEONATAL INTENSIVE CARE UNIT

8.1 FEEDING OF THE CRITICALLY ILL CHILD IN NICU

The prevalence of malnutrition among critically ill children has not really changed in the last two decades. It is reported that 16-20% of children in the Paediatric Intensive Care Unit (PICU) develop acute protein-energy malnutrition within 24 hours. Both under and overfeeding are prevalent in the PICU and may result in large energy imbalances. Although nutrition support cannot prevent or reverse the metabolic response to injury, stress, inflammation or surgery, failure to prevent optimal nutrients during this stage may affect clinical outcome of the child. A multi-disciplinary team approach involving a registered dietitian, have shown better nutrition outcomes in critically ill children.

The role of registered dietician in PICU would be:

- To assess the nutritional status of the child
- To determine nutritional requirements and provide a nutritional care plan
- To determine the route of feeding
- Monitoring the feeding process and nutritional status

8.2 ASSESSMENT OF NUTRITIONAL STATUS

8.2.1 Anthropometry

Anthropometry such as weight, length, head circumference and mid-arm circumference is an important tool to determine nutritional status. However, it is very difficult to do accurate anthropometric measurements in the critically ill child due to fluid shifts, oedema and ascites, and other factors such as bandages, catheters and lines.

8.2.2 Clinical assessment

Clinical assessment includes a physical examination of nutrient deficiencies, the presence of oedema or dehydration, the presence of pressure sores, the vital signs, temperature and functioning of the gastro-intestinal tract (GIT).

8.2.3 Biochemistry

There are Intensive Care Units that use serum albumin concentrations to determine the protein status. Albumin however has a long half-life of 14-21 days and cannot be used to determine the immediate protein status. Albumin concentrations can also be affected by dehydration, sepsis, trauma, liver disease and medications. Pre-albumin is a better marker of protein intake. This protein has a half-life of 24-48 hours and can be used to regularly monitor the protein status. Pre-albumin serum concentrations may be falsely elevated in renal failure and lower in liver disease. Low levels of serum urea, total protein, pre-albumin and retinol binding protein can be indicative of insufficient nutrient intake, especially protein intake.

C-reactive protein (CRP) can be used as an index to measure the acute-phase injury response. In children with burn injury, the CRP rises within 12-24 hours of the stress. During the acute phase response, levels of serum pre-albumin decreases while CRP concentrations increase and return to normal once the acute

phase injury response is over. This is a helpful marker to determine and adjust protein needs.

Lowered serum levels of copper, zinc and selenium and the fat-soluble vitamins A and E could be a marker for long standing malnutrition in children. Hypophosphatemia, hypokalemia, hypomagnesemia and thiamin deficiency are indicative of a child being at risk of refeeding syndrome. Iron-study together with folate and vitamin B_{12} can be done to confirm the presence of nutritional anaemia.

8.2.4 Blood gases

Avery low PO_2 count is usually contra-indication to feed a child in NICU. When high PCO_2 counts are present, the fat and carbohydrate distribution of a feed needs to be adjusted.

8.3 NUTRITIONAL REQUIREMENTS

When the critically ill child's feeding is planned, the energy (calories), protein, carbohydrate, fat, vitamins and minerals as well as the fluid intake should be taken into consideration.

8.3.1 Energy

In the critically ill child, metabolic abnormalities of the energy metabolism occur. It is thus of great importance to refer the child to a registered dietician to determine macro-nutrient requirements as accurately as possible. The consequences of getting these requirements wrong can either lead to *overfeeding*, causing diet induced thermogenesis, increased CO_2 production, impaired liver function or the deposition of fat rather than lean body mass and increased risk of infection secondary to hyperglycaemia, or *underfeeding* causing depletion of fat and energy stores, compromised immune system, increased risk for infection, poor wound healing and increased mortality. For instance, children with head injuries are easily underfed. The meganism of brain injury in children are completely different from adults and studies have found that the mean energy expenditure are 130-170%

higher than predicted levels. Feeding these children enough calories and protein are critical to the recovery process. Obese children in ICU also need feeding, but ideal body weight is used rather than the actual body weight.

Risk of over feeding in PICU	Risk of underfeeding in PICU
Mechanically ventilated children	Children with severe burn injury
Physical handicapped children	Children with sepsis
Children who are sedated	Children with traumatic brain injury
	Children who had surgery

8.3.2 Protein

During critical illness and recovery from surgery or trauma, the body responds with an increased protein catabolism and turnover. If not fed sufficient protein, these patients manifest with negative protein and nitrogen balances, because of reduced protein stores available in children. This leads to weight loss, breakdown of muscle and immune dysfunction. If the body continues to break down muscle mass from critical organs to provide sufficient protein for the stress response, the loss of diaphragmatic, intercostal and cardiac muscle will happen. The loss of intercostal muscle leads to respiratory compromise. To preserve skeletal muscle protein mass is the most important nutrition intervention in the critically ill child.

8.3.3 Carbohydrate

Carbohydrates are important to provide the body with energy. In critical illness, glycogen stores are limited and quickly depleted. The body uses glucose as the main energy source for the erythrocytes, the brain and the renal medulla. In children with respiratory distress less carbohydrates should be given.

8.3.4 Fat

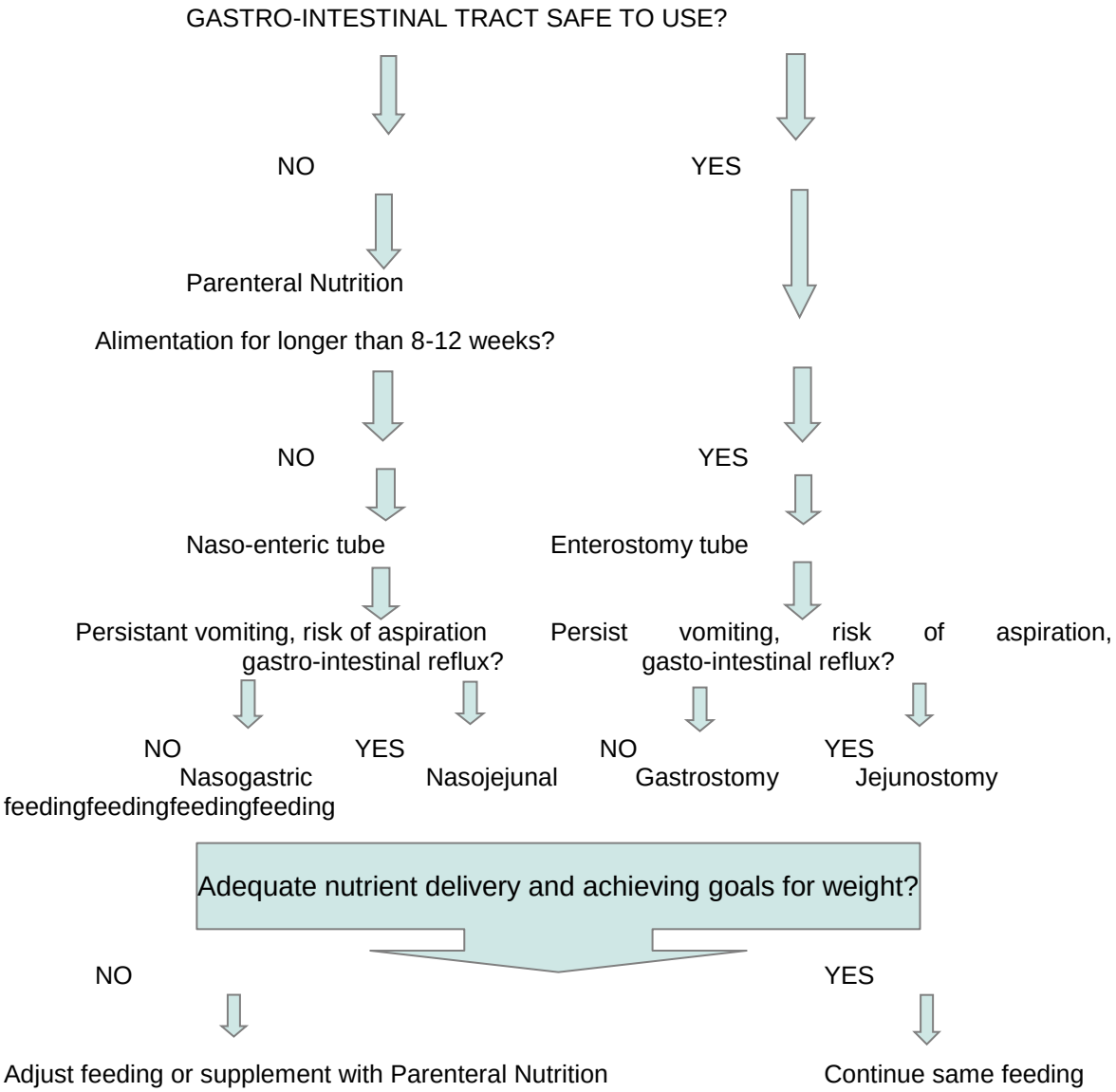
Research has shown that critically ill children have a higher rate of fat oxidation. Restriction is therefore contra-indicated in children, except for certain medical conditions like pancreatitis, chylothorax etc.

8.3.5 Fluid

Paediatric patients' fluid requirements are influenced by medical and environmental factors. High urinary output, excessive vomiting, fever, diarrhoea and drains can increase the fluid requirements. Other medical conditions such as renal, cardiac and respiratory disease may lower the fluid requirements. When fluids are restricted, calorie-dense formulas can be used to meet nutritional requirements. If more fluid is needed for maintenance than the formula feed provides, additional water should be given inbetween or with the feed.

8.3.6 Route of feeding

Nutrition can be administered via the enteral or parenteral route if a normal oral diet does not meet the nutritional requirements. The following algorithm can be used to select the appropriate route:



8.3.6.1 Enteral feeding

Enteral feeding has a huge advantage due to the fact that it helps to keep the gastro-intestinal function intact and prevents pancreatic and biliary flow dysfunction. It is advised to start the enteral feeding process as soon as possible, within 24-48 hours after admission, providing that the child is hemodynamically stable.

INDICATIONS FOR PEDIATRIC ENTERAL NUTRITION

1. Inadequate oral intake, inability to suck or swallow

- Neurological handicapped and degenerative disorders
- Severe developmental delay
- Tumours of oral cavity, head and neck cancer
- Trauma
- Coma, mechanical ventilation
- Severe gastro-esophageal reflux
- Protein-energy malnutrition due to food deprivation

2. Increased nutritional requirements due to chronic illness:

- Cystic fibrosis
- Inflammatory bowel disease
- Liver disease, kidney disease
- Congenital heart disease
- Inherited metabolic diseases

3. Disorders of digestion and absorption

- Short bowel syndrome
- Malabsorption syndrome due to food allergies and intolerances
- Enteritis due to chronic infection
- Protracted diarrhoea of infancy
- Pancreatic insufficiencies
- Severe primary and acquired immuno-defiency
- Intestinal fistulae

4. Congenital anomalies

- Tracheo-oesophageal fistula
- Oesophageal atresia
- Orofacial malformations

5. Primary disease management

- Chron's disease
- Short bowel syndrome

6. Altered metabolism and metabolic inborn errors

- Glycogen storage disease
- Very long chain fatty acid disorders

7. Failure to thrive

- Inadequate growth or weight gain for more than a month, under 2 years of age
- Weight loss or no weight gain for more than 3 months, over the age of 2 years
- Triceps skin fold measurements are consistently lower than the 5th percentile for age
- If it takes longer than a total of 4 hours per day to feed a disabled child

8.3.6.2 Contra-indications for enteral feeding

- Necrotizing enterocolitis
- Bowel obstruction or ileus
- Hemodynamic instability
- Persistant vomiting or diarrhoea
- Acute abdominal distention
- Gastric, small or large bowel fistula
- Upper gastro-intestinal bleeding

8.3.6.3 Route and tube placement for enteral feeding

The following routes can be used to provide enteral nutrition: oral gastric (OG), nasogastric (NG), nasojejunal (NJ) or gastrostomy. Oral gastric and nasogastric tubes are usually easy to place. OG-tubes are sometimes placed in children with facial abnormalities or cleft palate. NJ-tube feeding or post-pyloric feeding can be given in children with a high risk of aspiration or that cannot tolerate gastric feeding. The position of the NJ-tube must be confirmed with an X-ray. The long term use of NG and NJ tubes can lead to gastro-oesophageal reflux and esophagitis. If enteral feeding is going to be administered for longer than 8-12 weeks, it is strongly advised that a gastrostomy tube be placed.

8.3.6.4 Method of infusion

Enteral feeds can either be given as boluses or as continuous feeds. A regimen should be prescribed to meet the individual requirements of the child. Bolus feeds are given with a syringe 2, 3 or 4 hourly through the day. This method of feeding mimics a physiologically normal feeding pattern and stimulates the normal hormonal and enzyme feeding response. Tubes should be aspirated before each feed to prevent over-filling of the stomach. However, if a child has a jejunostomy tube, the feeds should always be given continuously to prevent dumping syndrome. Continuous feeds are delivered using a pump with a constant infusion rate over 24 hours. There are studies that indicate that continuous feeds are better tolerated by critically ill children. When continuous feeds are administrated there is also a lower risk for aspiration. Infants and children with malabsorption will benefit from this method of feeding. Continuous feeding is also advised for primary disease management (Chron's disease, short bowel etc.). When a child is on continuous feeds the infusion should be stopped for 4 hours to allow the gastric pH to return to normal – this will help to prevent bacterial overgrowth and migration in the GIT. Continuous feeds can however accumulate in the stomach of those children with gastric stasis. This can lead to gastric rupture. The continuous delivery of enteral feeds can also interfere with the absorption of medication. Trophic feeding is introduced when enteral feeding is poorly tolerated. Feeds are usually started at 1 ml/h and gradually increased to 10mls/h continuously. This feeding method is contra-indicated in children with ileus, obstruction or post gastro-intestinal surgery.

8.3.6.5 Feeding selection

The dietician plays an essential role as part of the medical team and is the expert to assess and determine a suitable feed. Semi-elemental feeds are sometimes better tolerated in children after severe trauma or injury or after a long period of parenteral nutrition. Children with food allergies, metabolic syndromes, cerebral palsy or neurological impairment may also require elemental or semi-elemental feeds. The dietician can also compose a modular feed in cases of severe multiple food allergies or metabolic disease.

8.3.6.6 Enteral feed hanging time

The hanging time of enteral feeds should be closely monitored due to the risk of contamination. Enteral feeding sets should be changed every 24 hours and bolus feeding systems should be thoroughly cleaned with hot water and rinsed with sterile water at the end of each feed. Special attention should be given to feeds prepared from powders as powders are not sterile. These feeds create an ideal medium for the growth of bacteria. Some of these bacteria like Enterobactersakazakii can cause neonatal meningitis, sepsis and necrotising enterocolitis. It is therefore strongly advised to give liquid nutritional products, especially for the critically ill child.

8.3.6.7 Monitoring of enteral feeding

8.3.6.7.1 Feeding tolerance

Clinical signs of feeding intolerance may include: coughing, abdominal distention or pain, restlessness, obvious signs of discomfort, diarrhoea or vomiting. If these signs are observed, the feed should be stopped and the child's status, the tube placement, the rate and delivery of the feed and also the strength and choice of feed should be re-assessed. Drug-nutrient interactions can also be a cause of feeding intolerance.

8.3.6.7.2 Anthropometrics

Weight and height should be recorded before tube feeding is started. The weight should be monitored at least 2-3 times per week. Children that require tube feeding for longer than 3 weeks should also be monitored measuring the length and skin fold thickness. In children up to 2 years of age, the head circumference should also be measured and then monitored monthly in hospital for children on long term tube feeding.

8.3.6.7.3 Biochemistry

The same biochemical markers used to assess the critically ill child, should also be used to monitor the patient. In very malnourished or ill children the values should be monitored on a daily basis. In more stable patients, the biochemistry can be monitored twice weekly.

8.3.6.7.4 Stools

A change in stool characteristics does not necessarily mean that the enteral feed is not tolerated. Semi-elemental or elemental feeds often produce green, mucus-like stools.

8.3.6.7.5 Parenteral Nutrition

Parenteral nutrition (PN) are indicated when the gastro-intestinal tract does not function and the enteral route cannot be used to meet the child's nutritional requirements. Parenteral nutrition should be used with great care for it is expensive and inappropriate use can worsen a child's clinical state. Whenever possible parenteral nutrition should be combined with some enteral nutrition (provided that the child is hemodynamically stable) to try and keep the gastro-intestinal function intact. In very malnourished children, it is advised to start PN slowly and then gradually increase the volume to prevent refeeding syndrome.

Each child should be individually assessed to determine the need for parenteral nutrition. The following circumstances can be indicative of replacing or supplementing enteral nutrition with parenteral nutrition:

INDICATIONS OF PEDIATRIC PARENTERAL NUTRITION

1. Limited tolerance of enteral feeding

- Premature or low birth weight infants
- Surgical abnormalities like gastrochises or intestinal atresia
- Short bowel syndrome
- Protracted diarrhoea
- Necrotising enterocolitis
- Malabsorption syndromes
- Chemotherapy or bone marrow transplant
- Inflammatory bowel disease

2. Children who may require additional nutritional support

- Trauma or burns
- Chronic renal failure
- Malignant disease
- Liver disease

8.3.6.7.5.1 General principals when prescribing parenteral nutrition for children

Children differ greatly from adults; this should be taken into account when prescribing PN. Children are still growing and would need sufficient nutrition to support that, especially if long term PN is given. Infants are very vulnerable as their brains grow rapidly during the first year of life – malnutrition and biochemical instability should be avoided. Children's macro and micro-nutritional requirements change as they grow older and they also have lower nutritional stores than adults. A low birth weight neonate may only survive 4-7 days without nutrition, but a one year old child can survive a month - this should be taken into account as to when PN is started. In South Africa, standard bags with different compositions of PN are available to use. Tailored made PN can be made for specific diseases and circumstances. PN solutions expire and are not sterile after 24 hours and should be

discarded.

8.3.6.7.5.2 Monitoring of Parenteral Nutrition

The same anthropometric and biochemical markers used to assess the critically ill child, (see paragraph 8.2.1 and 8.2.3) should also be used to monitor the child on parenteral nutrition.

The following should be monitored in stable patients on PN as well:

Glucose	Monitor at the start of therapy	Monitor twice weekly
Electrolytes	Monitor at the start of therapy	Monitor twice weekly
Intralipid level	-	Monitor twice weekly
Complete blood count	-	Monitor twice weekly
Urea, phosphate, calcium, conjugated bilirubin, albumin, magnesium	Monitor at the start of therapy	Monitor once a week
AST, alkaline phosphatase, creatinine, acid base	Monitor at the start of therapy	Monitor once a week

8.4 FEEDING OF PREMATURE AND LOW BIRTH WEIGHT INFANTS IN THE NEONATAL INTENSIVE CARE UNIT

A premature infant is any baby born before 36 weeks of gestation. An infant born with a weight of less than 2.5 kg is a low birth weight (LBW) infant, regardless of gestation. A very low birth weight (VLBW) weighs less than 1,5 kg and an extremely low birth weight (ELBW) infant less than 1 kg.

Feeding of the premature infant are challenging due to multiple problems these babies encounter such as respiratory, renal, cardiovascular, gastro-intestinal, hepatic, haematological and immune related complications. Failure to provide

sufficient protein and calories leads to poor growth that results in short and long term complications such as necrotising enterocolitis (NEC), bronchopulmonary dysplasia, late onset sepsis, cerebral palsy and other neurological abnormalities as well as developmental impairment. Overfeeding can lead to metabolic syndrome.

A multi-disciplinary team approach where the doctor, nursing staff and registered dietitian works together, is of the utmost importance to achieve optimal nutrition in these infants.

8.4.1 Nutrition

Nutrition for premature infants is an urgency because of the limited metabolic reserves they have. A 1 kg baby only has 1% fat stores in comparison with a 3.5 kg baby that has 16% stores. If a 1 kg baby is left unfed, it will only survive for 4 days.

The goal of nutritional support for pre-term infants are:

- To maintain the anabolic state of the foetus
- To mimic intrauterine growth
- To provide optimal protein and calorie ration to gain lean muscle mass

Nutritional support for the pre-term infant occurs in two phases. The first phase is just after birth where the infant is fed via the parenteral route. Trophic feedings are given to help the immature gastro-intestinal tract mature. In the second phase, enteral nutrition should provide all the nutrients needed for growth.

8.4.2 Parenteral Nutrition (PN)

PN should be initiated within 24 hours after birth. Studies have shown that infants who received PN within the first 24 hours of life, reached their full enteral feeds faster. Failure to provide adequate nutrition, especially protein have a negative long term effect on organ growth, stature, cognitive and neuro-development. A registered, experienced dietitian should be consulted to determine and advise on

the requirements of the preterm infant, as the nutritional requirements of these infants are poorly recognised in most units world wide.

Amino acids should be provided at 3.5-4.0 g/kg/day for positive protein balance and growth. Total energy for the VLBW infants should provide 90-100 kcals/kg and for the ELBW infants 105-115 kcals/kg. Glucose of 6-8 mg/min/kg should be started as soon as possible after birth. Preterm infants do not have glucose reserves and in early gestations, the largest glucose consuming organ is the brain. Infusions of more than 12 mg/min/kg can lead to hyperglycaemia. Lipid should provide at least 0.5g/kg/day to prevent essential fatty acid deficiency.

In South Africa, standard PN bags are available to use in the NICU. The danger exists that preterm infants are often under or overfed and that individual requirements are not calculated to meet the specific needs.

8.4.3 Enteral Nutrition

8.4.3.1 Fluid requirements

In the initial phase after birth, fluid management is complicated. A balance needs to be achieved between fluid losses due to skin permeability and not overloading the kidneys due to renal immaturity. Enteral fluid prescription for most infants range form 150mls/kg/day – 180mls/kg/day. If an incubator, overhead heater of phototherapy is used, 10% extra fluid should be given. In very sick infants fluids may be restricted to 120-130 mls/kg/day. Nutritional intakes should be optimised within the fluid allowed.

8.4.3.2 Energy

Premature infants have high energy demands to mimic intra-uterine growth rate. When premature milk formula is given at 150-180 mls/kg/day, the energy requirement is usually met and no fortification is needed. Breastmilk is the preferred milk to give these infants, but does not provide enough energy and should be supplemented with a breastmilk fortifier.

8.4.3.3 Protein

Premature infants have very high protein needs and can tolerate protein because pancrease enzymes and gastrin are already present. The protein in breastmilk is well metabolised. Protein supplementation of breast milk with breast milk fortifiers have shown to increase the short term weight gain, head and linear growth.

8.4.3.4 Fat

The smaller the infant, the higher the risk of fat malabsorption due to low pancreatic lipase and bile salts. Poly-unsaturated fats are better absorbed than short chain fatty acids. Medium chain trigliserides (MCT) do not need bile salts to be metabolised and are a good source of fat and energy for those infants that are fluid restricted and not able to meet nutritional requirements. If MCT-oil is used for fortification, care should be taken not to exceed 1 kcal/ml .

8.4.3.5 Carbohydrate

Glucose is well tolerated for the glucosidase enzymes are already active in very small premature infants. Lactase levels are low, but feeding milk that contains lactose, will help to develop the lactase activity.

The following table shows the macro-requirements for the stable premature infant tolerating full feeds:

Energy	120-150 kcals/kg/day
Protein	3.5-4 g/kg/day
Fat	4-6 g/100 kcals/day
Carbohydrate	10-14 g/kg/day

The gastro-intestinal tract must be used as soon as possible. Oro-gastric (OG) or naso-gastric (NG) tubes are usually put in place when trophic feeds are introduced. The nutrition team at Toronto, Ontario, Canada uses the following protocol to introduce enteral feeds in stable preterm infants (June 2007):

Weight	Milk	Method	Starting volume	Frequency	Increased by	Full feeds (mls/kg/day)

1000-1250g	EBM/Pre-term formula	OG/NG & introduce kangaroo care	1-2 ml	2 hourly	1 ml, 12 hourly	140-160 mls
1250-1500g	EBM/Pre-term formula	OG/NG & introduce kangaroo care	1-2 ml	2 hourly	1-2 mls, 12 hourly	140-160 mls
1500-2000g	EBM/Pre-term formula	OG/NG & introduce kangaroo care	2-3 ml	3 hourly	2 ml, 12 hourly	160-180 mls
2000-2500g	EBM/Pre-term formula	OG/NG & introduce kangaroo care	4-5 ml	3 hourly	3 ml, 12 hourly	160-180 mls

Tolerance is indicated by gastric aspirates before feeding as well as abdominal distention. If gastric aspirates are more than 1-2 mls, feeds should not be increased.

8.4.3.6 Type of feed

Breast milk is the preferred milk to give. Infants can reach their full feeds faster if breast milk is given because digestion is easier and toleration better. If breast milk is not available, fortified donor breast milk or preterm infant formulas can be given. It is strongly advised that ready-to-feed preterm infant formulas are used in the neonatal intensive care unit. Powder formula's are not sterile and increase the risk of bacterial contamination and NEC. Semi-elemental formula's, soy based formulas and full term infant milk formulas are contra-indicated for pre-term infants.

During the first 2 weeks of a premature infant's life, expressed breast milk can meet the nutritional requirements, there after a multi-nutrient fortifier needs to be added to provide the nutritional demand of these infants. Protein content of preterm human milk decreases with up to 25% after the first few weeks of lactation. Breast milk should be fortified just before feeding time to reduce the risk

of bacterial contamination and avoid loss of immunological factors. The following metabolic complications can occur if breast milk is given without fortifiers:

- Zinc deficiency
- Hypoproteinemia
- Hyponatremia
- Ostoepenia

Infants should be able to tolerate full feeding volume (100-150mls/kg/day) before fortifiers are added. Breast milk should be fortified until infant can feed successfully form the breast or until a weight of 1.8-2.5 kg is reached.

Preterm infants have an underdeveloped gastro-esophageal sphincter and very slow gastric emptying. This leads to an increased incidence of aspiration and reflux. For this reason, the babies should not be lying flat when fed. Feeds are better tolerated when baby is held upright between mother's breasts and milk given via gravity pump. If baby has severe reflux, feeds should not be stopped, but rather reduced in volume. Feeds can also be given two hourly, instead of three hourly. Some infants have small aspirates no matter what the feeding volume and yet tolerate the feeds. Aspiration of 50% of a bolus feed is usually accepted and in this case the feed should not be stopped, but only the volume reduced. Undigested milk may indicate another underlying cause such as:

- that the milk is not tolerated
- that the infant is receiving a too large volume of milk
- intestinal obstruction or NEC
- poor gastro-intestinal motality

8.4.3.7 Micro-nutrient supplementation

The following supplements should be given to premature infants:

- **Multivitamin drops**

Multivitamin drops like Vidaylin® should be started at 0.3ml/day as soon as full enteral feeds are given. If a preterm infant formula is given and it contains sufficient vitamins, supplementation is not needed.

- **Iron**

Iron stores are low in preterm infants, and should be supplemented to avoid depletion. Iron is prescribed when full enteral feeds are given and no sign of infection present. An amount of 2 mg/kg/day to 15 mg/kg/day can be prescribed. The following guideline can be used to determine the dosage of iron:

Birth weight < 1.0 kg	4 mg of elemental iron/kg/day
Birth weight 1.0-1.5 kg	3 mg of elemental iron/kg/day
Birth weight 1.5-2.5 kg	2 mg of elemental iron/kg/day

- **Vitamin D**

Vitamin supplementation should be given to prevent the development of osteopenia rickets. The recommendation is to provide 400 IU of vitamin D daily.

8.5 MONITORING OF NUTRITIONAL STATUS

8.5.1 Anthopometry and growth charts

Fenton growth charts (revised in 2013) for premature boys and girls can be used to measure weight, length and head circumference.

- *Weight gain*: Infants can initially lose 5-15% of their birth weight during the first week of life. Birth weight should ideally be regained within 10-14 days after birth. The ideal weight gain should be a minimum of 15 g/day.

- *Length*: The ideal length gain is 0.8-1.0 cm/ week.

- *Head circumference:* The ideal growth in head circumference is 0.5-0.8 cm/week

8.5.2 Biochemistry

During the first week of life, serum electrolytes, creatinine, glucose and urea nitrogen are monitored daily.

The following monitoring schedule can be used for stable NICU infants on Parenteral Nutrition:

Parameter	First 3 weeks on PN	After 3 weeks on PN
Glucose	Twice weekly	1-2 times per week
Full Blood Count	Once a week	Once a week
Electrolytes	Twice weekly	1-2 times per week
Cholesterol and Trigliserides	Once a week	Once a week
Urea + creatinine	Twice weekly	Once a week
Calcium + magnesium	Not applicable	Every 2 weeks
Phosphate	Not applicable	Every 2 weeks
Bilirubin	Not applicable	Every 2 weeks
Serum Alanine Aminotransferase	Not applicable	Every 2 weeks
Albumin	Not applicable	Every 3 weeks

The Metropole Pediatric Interest Group of the Western Cape uses the following biochemical indicators to evaluate if suffiecient nutrients are provided:

Parameter	These values indicate a deficiency	Interpretation
Serum urea	< 1.8 mg/L	Insufficient nutrient and protein intake
Serum total protein	< 44g/L	Insufficient nutrient and protein intake
Serum pre-albumin	< 10 mg/dL	Insufficient nutrient and protein intake
Serum retinol binding protein	< 1.05 mg/dL	Insufficient nutrient and protein intake
Serum alkaline phosphatase	< 450 IU/L	Insufficient nutritional intake of calcium and phosphorus: decreased bone mineral deposition
Serum phosphate	< 4.5mg/dL	Insufficient phosphate intake

8.6 KANGAROO MOTHER CARE

Kangaroo mother care (KMC) is the continuous skin-to skin contact of mother with baby. Baby can be exclusively breastfed, or being held between mother's breasts in a “sitting” position while milk is given via gravity pump. KMC can be started after birth as soon as baby is stable and can be continued at home. KMC plays a very important role in the overall health and growth of the preterm infant as well as the

milk production of the mother. Recent meta-analysis study done by Lawn *et al*[273] found that KMC was associated with less morbidity and mortality in preterm infants weighing less than 2000g.

KMC also has the following advantages:

- Less nosocomial infections. Contact with baby's skin increases the amount of anti-bodies produced by the mother, which baby gets in via the breast milk.
- Less apnoea and demand for oxygen.
- Better temperature regulation.
- Better heart rate
- Earlier hospital discharge
- Less crying

8.7 DISCHARGE AND FOLLOW-UP

The following feeding criteria should be met before infants can be discharged:

- Baby must be breastfeeding successfully and gaining weight while doing so. If infant is discharged with a subnormal weight for postconceptional age, breast milk at home must be fortified with a human milk fortifier.
- If baby can not be breastfed, a nutrient enriched post-discharged formula should be prescribed. These formulas contain higher amounts of protein, energy and micro-nutrients to meet the higher demand of nutrients.
- Infants are usually discharged with a weight of 1.8-2.0 kg and gestational age of 34 weeks and older.
- Baby must be able to gain the recommended 15-30 g per day
- Multi-vitamin drops of 0.6 mls per day and elemental iron of 1-2 mg/kg should be prescribed before discharge.
- Follow-up appointment must be made with the dietitian to monitor and evaluate infant's progress.

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[273] Lawn JE *et al* "'Kangaroo mother care' to prevent neonatal deaths due to preterm birth complications" (2010) *International Journal of Epidemiology* 39:144-154.

Post-discharge formula can be given until 6-9 months of age or until catch-up growth is achieved.
A multivitamin- and iron supplement at standard dose should be given for the first year of life if baby is breastfed.

If the multivitamin supplement does not contain 400 IU of vitamin D per day, the latter should also be supplemented until one year of age in breastfed infants.
Ideally catch-up growth should be achieved before 2 years of life. The following growth rates can be used to monitor growth in preterm born infants:

Weight gain:	First 3 months post-discharge:	25-30 g/day
	3-12 months post discharge:	10-15 g/day
Length gain:	First 3 months post-discharge:	0.7-1.0 cm/week
	3-12 months post discharge:	0.4-0.6 cm/week

CHAPTER 9

(Mirissa Meyer)

ETHICAL GUIDELINES IN NEONATAL CARE: AUDIOLOGY

9.1 NATURE OF SPEECH-LANGUAGE THERAPY SERVICES IN NEONATAL INTENSIVE CARE

Audiologists form part of the peripheral team providing services to infants in the neonatal intensive care unit (NICU) to prevent newborn and infant hearing loss as far as possible, identify, diagnose and to treat newborns and infants with disabling hearing loss as early as possible.[274] This is to ensure optimum, cost effective solutions that enable individuals to communicate effectively, allowing them to develop to their maximum potential, attain optimal quality of life and thereby to secure their full participation in, and contribution to, society and the country's economy.[275]

9.2 PREVALENCE AND OUTCOMES OF HEARING LOSS IN NEONATES

Hearing loss is referred to as the silent, overlooked epidemic of developing countries because of its invisible nature which prevents detection through routine clinical procedures.[276] It is referred to as an epidemic because of its high prevalence, being the most frequently occurring birth defect, affecting more than twice the number of neonates than all other screenable newborn disorders

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274 Health Professions Council of South Africa. Professional Board for Speech, Language and Hearing Professions (2007) *Early Hearing Detection and Intervention Programmes in South Africa, Position Statement 2007* 1-42.

275 *Ibid*; Yoshinaga-Itano C and Gravel JS "The evidence for universal newborn hearing screening" (2001) *American Journal of Audiology* 10:62-64; Olusanya BO, Ruben RJ and Parving A "Reducing the burden of communication disorders in the developing world" (2006) *Journal of the American Medical Association* 296(4) 441-444.

276 Swanepoel *et al* "Infant hearing loss – silent epidemic of the developing world" (2005) *Audiology Today* 17(4):12-16; Health Professions Council of South Africa. Professional Board for Speech, Language and Hearing Professions (2007) 1-42.

combined.[277] In South Africa an estimated 17 babies are born with a significant permanent bilateral hearing loss every day.[278] These infants can only be detected early enough for optimal intervention outcomes through widespread newborn and infant hearing screening programmes using objective (oto-acoustic emissions and auditory brainstem response screeners) screening technologies.[279] Even though it is not a life-threatening condition, failure to intervene in time renders it a severe threat to critical quality of life indicators.[280] The adverse effects of hearing loss on language and cognitive development, as well as on psychosocial behaviour, academic accomplishment and later vocational prospects are widely reported against the established benefits of early intervention whereby children who were identified and received intervention early (within the first six months of life) have linguistic, speech and cognitive developmental outcomes potentially matching those of their normal hearing peers.[281]

277 O'Neal J *et al* "Neonatal hearing screening: Follow-up and diagnosis" in Roeser RJ, Valente M and Hosford-Dunn H (eds.) *Audiology: diagnosis* (2000); Smith R J H *et al* "Sensorineural hearing loss in children" (2005) *Lancet 365:*879-890; Health Professions Council of South Africa. Professional Board for Speech, Language and Hearing Professions.(2007) 1-42.

278 Swanepoel D "Early detection of infant hearing loss in South Africa" (2009) *South African Medical Journal 99*(3):158-159.

279 Swanepoel D *et al* "Early hearing detection and intervention in South Africa" (2009) *International Journal of Pediatric Otorhinolaryngology* 73(6):783-786; Korver AMH *et al* "Newborn hearing screening vs later hearing screening and developmental outcomes in children with permanent childhood hearing impairment" (2010) *Journal of the American Medical Association 304*(15):1701-1708; Morton CC and Nance WE "Newborn hearing screening – a silent revolution" (2006) *New England Journal of Medicine* 354:2151-2164; Joint Committee on Infant Hearing (JCIH) "Year 2007 position statement: Principles and guidelines for early hearing detection and intervention programs" (2007) *Pediatrics,* 120:898-921; Health Professions Council of South Africa Professional Board for Speech, Language and Hearing Professions (2007) 1-42; World Health Organization (2010) *Newborn and Infant Hearing Screening: Current Issues and Guiding Principles for Action.*

280 Mehl AL and Thomson V "Newborn hearing screening: The great omission" (1998) *Pediatrics*, 101(1):1-6; Olusanya BO *et al* "Infant hearing screening: route to informed choice" (2004b) *Archives of Disease in Childhood* 89:1039-1040; Swanepoel D *et al* "Universal Newborn Hearing Screening In South Africa: A first-world dream?" (2004) *South African Medical Journal* 94(8):634-635.

281 Kennedy C *et al* "Universal newborn screening for permanent childhood hearing impairment: and 8 year follow up of a controlled trial" (2005) *Lancet* 366:660-662; Moeller MP "Early intervention and language development in children who are deaf and hard of hearing" (2000) *Pediatrics* 106(3):1-9; Yoshinaga-Itano C "Levels of evidence: universal newborn hearing screening (UNHS) and early hearing detection and intervention systems (EHDI)" (2004) *Journal of Communication Disorders* 37:451-465; Health Professions Council of South Africa. Professional Board for Speech, Language and Hearing Professions (2007) 1-42.

9.3 RIGHTS OF INFANTS AND FAMILIES

- All children with significant hearing loss have the basic human right to access human communication, regardless of where they are born, of their race, ethnicity or national origin, of what their family income is, the level of education of their parents, or their type of occupation.[282] However, only 7.5% of public sector and 53% of private sector hospitals nationally provide some form of neonatal or infant hearing screening and less than 1% public and only 14% private hospitals provide universal screening.[283]
- That being said, because screening is not yet legislated in South Africa, in many hospitals where screening is offered, parents/families have the right to decide to accept or decline newborn hearing screening services. The goal of informed choice in NICU's is therefore to ensure that the family's decision to accept or decline the screening stems from an understanding of the consequences of each course of action.[284] Comprehensive, unbiased information from professional, educational and consumer organisations should therefore be provided to allow families to make informed choices.[285]
- Equal opportunities for children with hearing loss are attainable through effective early hearing detection and intervention programmes and a growing body of evidence suggests long-term economic benefits to initial investments in these programmes.[286]

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282 Yoshinaga-Itano C and Thomson V "The work of the Village: Creating a new world for children with hearing loss and their families" (2008) *International Journal of Audiology 47* (Suppl. 1) S14-S22.

283 Theunissen M and Swanepoel D "Early hearing detection and intervention services in the public health sector in South Africa" (2008) *International Journal of Audiology 47* (Suppl. 1) S23-S29; Meyer ME and Swanepoel D "Newborn hearing screening in the private health care sector – a national survey" (2011) *South African Medical Journal* 101(9):665–667.

284 Olusanya BO *et al* "Benefits and challenges of newborn hearing screening for developing countries" (2004) *International Journal of Pediatric Otorhinolaryngology* 68:287-305; Health Professions Council of South Africa. Professional Board for Speech, Language and Hearing Professions (2007) 1-42.

285 Health Professions Council of South Africa. Professional Board for Speech, Language and Hearing Professions (2007) 1-42.

286 Belli PC *et al* "Investing in children's health: what are the economic benefits?" (2005) *Bull World Health Organ* 83:777-784; Kennedy C and McCann D "Universal neonatal hearing screening moving from evidence to practice" (2004) *Archives of Disease in Childhood - Fetal and Neonatal Edition* 89:F378-F383; World Bank (2005) *World Development Report 2006: Equity and Development*.

9.4 ROLES AND RESPONSIBILITIES

9.4.1 Departments and agencies

The Ministries of Health, Social Development and Education should be the leading role players charged with the design and implementation of early identification, assessment and education programmes for learners with disabilities in the age group 0-9 years.[287] A lead agency in conjunction with tertiary training institutions should be appointed to coordinate the implementation, regulation and data management for early hearing detection and intervention programmes in South Africa.[288]

9.4.2 Professionals

As experts in infant hearing loss, **audiologists** serve in the capacity of programme manager supervising the early hearing detection and intervention programme. In terms of the hearing screening component the audiologist develops the programme according to each context's characteristics and resources, manages the programme, quality assures, trains support personnel, coordinates services and ensures effective transition to evaluation, habilitation and intervention services.[289]

Paediatricians serve as the advocate for the child's medical welfare holistically. Paediatricians, especially for screening programmes in NICU's are the key professionals overseeing the infant's health and well-being. Screening programmes must therefore be developed and managed in close collaboration and partnership with paediatricians and **paediatric nurses** as the primary medical practitioners responsible for infants in the NICU and well-baby nurseries.[290]

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287 Department of Education (2001) *White paper: Special Needs Education: Building an Inclusive Education and Training System.* http://www.info.gov.za/whitepapers/2001/educ6.pdf; Health Professions Council of South Africa. Professional Board for Speech, Language and Hearing Professions (2007) 1-42.

288 Health Professions Council of South Africa. Professional Board for Speech, Language and Hearing Professions (2007) 1-42.

289 *Ibid*.

290 *Ibid*.

9.4.3 Principles

The development of early hearing detection and intervention systems in South Africa has to be family-centred, community based and available to all infants in a comprehensive, coordinated and timely manner.[291]

The following **six principles** are provided as the foundation for effective and accountable early hearing detection and intervention systems in South Africa.

1. All infants are afforded access to hearing screening using a physiologic measure. For NICU graduates, screening has to be conducted at discharge. For healthy baby graduates, screening could be conducted at discharge or at immunisation visits at Primary Health Care clinics. These aspects constitute Universal Newborn and Infant Hearing Screening in South Africa.
2. All infants are afforded access to an effective referral system once they do not pass the initial screen and any subsequent rescreen in order to confirm diagnosis by 3 months of age (no later than 4 months).
3. All infants with confirmed permanent hearing loss receive services before 6 months (no later than 8 months of age). Prompt access to assistive hearing devices is ensured and intervention services are provided within interdisciplinary programmes that are family-centred and asset-based. Programmes need to build on informed choice and recognition of and respect for cultural beliefs and traditions of families.
4. All infants who pass the initial screening for bilateral hearing loss but who demonstrate risk indicators (listed below) for progressive, late-onset bilateral hearing loss or other auditory disorders and/or speech and language delay receive ongoing monitoring by caregivers informed of the risks and the expected communication developmental milestones.
5. Infant and family rights are guaranteed through upholding ethical practice in terms of informed choice and consent, and appropriate protection of

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[291] *Ibid*; Joint Committee on Infant Hearing (JCIH) "Year 2007 position statement: Principles and guidelines for early hearing detection and intervention programs" (2007) *Pediatrics* 120:898-921.

hearing screening evaluation and intervention results in agreement with other health care and later educational information.

6. Infant and family information regarding screening and possible follow-up assessments or services must be managed by integrated information systems to provide data for service development.

9.4.4 Guidelines

Newborn hearing screening:

- Universal neonatal hearing screening using electrophysiological measures (Otoacoustic Emissions (OAE) and Auditory Brainstem Responses (ABR)) is recommended as the golden standard for neonatal care. The golden Standard for NICU population is following an ABR protocol in order to ensure that Auditory Neuropathy Spectrum Disorder (higher prevalence amongst NICU graduates) is identified. In the healthy baby ward a two-stage protocol is recommended whereby ABR is conducted on failed OAE testing.[292]
- In cases where resource limitation make universal screening unfeasible risk-based screening must be pursued as an alternative. (Even though initial savings may be substantial by following a risk-based screening approach the long-term economic benefits of early identification of hearing loss will be severely compromised if a universal screening model is not applied).[293]
- The Joint Committee of Infant Hearing[294] has provided a comprehensive list of risk indicators (listed below) for hearing loss that can be used in risk-based screening approaches.

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292 Health Professions Council of South Africa. Professional Board for Speech, Language and Hearing Professions (2007) 1-42.

293 Yoshinaga-Itano C and Gravel JS "The evidence for universal newborn hearing screening". (2001) *American Journal of Audiology* 10:62-64; Yoshinaga-Itano C "Levels of evidence: universal newborn hearing screening (UNHS) and early hearing detection and intervention systems (EHDI)" (2004) *Journal of Communication Disorders* 37:451-465.

294 Joint Committee on Infant Hearing (JCIH) "Year 2007 position statement: Principles and guidelines for early hearing detection and intervention programs" (2007) *Pediatrics* 120:898-921.

Monitoring noise levels:

- The standard acceptable noise level recommended by the American Academy of Pediatrics for maternity/NICUs is 45 dB, and for incubators it is 58 dB.[295]
- Noise levels in neonatal wards are of concern to the developing infant. Various adverse health effects of noise for neonates include increased physiological stress, cardiovascular and respiratory problems, permanent auditory problems, and neurological impairment.[296]
- Typical sources of noise in these units include bradycardia alarms (55-88 dB), general conversation (58-64 dB), using the incubator top as a writing surface (59-64 dB), opening the plastic sleeve of the incubator (67-86 dB), dropping the head of the mattress (88-117 dB), and banging the incubator to stimulate an apneic premature infant (130-140 dB).
- It is therefore imperative that noise levels in these units be monitored periodically and kept sufficiently low.[297]

Risk Indicators

(Copied from JCIH, 2007 Position Statement)

Risk indicators associated with permanent congenital, delayed-onset, or progressive hearing loss in childhood are listed below (JCIH, 2007):[298]

"Risk indicators that are marked with a "*" are of greater concern for delayed-onset hearing loss".[299]

1. Caregiver concern* regarding hearing, speech, language, or developmental delay.
2. Family history* of permanent childhood hearing loss.

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295 American Academy of Pediatrics "Committee on Environmental Health. Noise: A hazard for the foetus and newborn" (1997) *Pediatrics*,100(4): 724–727.

296 *Ibid*.

297 *Ibid*.

298 Joint Committee on Infant Hearing (JCIH) "Year 2007 position statement: Principles and guidelines for early hearing detection and intervention programs" (2007) *Pediatrics* 120:898-921.

299 *Ibid*.

3. All infants with or without risk factors requiring neonatal intensive care for greater than 5 days, including any of the following: ECMO,* assisted ventilation, exposure to ototoxic medications (gentimycin and tobramycin) or loop diuretics (furosemide/lasix). In addition, regardless of length of stay: hyperbilirubinemia requiring exchange transfusion.
4. In utero infections, such as CMV*, herpes, rubella, syphilis, and toxoplasmosis.
5. Craniofacial anomalies, including those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies.
6. Physical findings, such as white forelock, that are associated with a syndrome known to include a sensorineural or permanent conductive hearing loss.
7. Syndromes associated with hearing loss or progressive or late-onset hearing loss, such as neurofibromatosis, osteopetrosis, and Usher syndrome; other frequently identified syndromes include Waardenburg, Alport, Pendred, and Jervell and Lange-Nielson.
8. Neurodegenerative disorders*, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth syndrome.
9. Culture-positive postnatal infections associated with sensorineural hearing loss*, including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis.
10. Head trauma, especially basal skull/temporal bone fracture* that requires hospitalization.
11. Chemotherapy*.

CHAPTER 10

(Alta Kritzinger)

ETHICS IN NEONATAL CARE: SPEECH-LANGUAGE PATHOLOGY

10.1 NATURE OF SPEECH-LANGUAGE THERAPY SERVICES IN NEONATAL INTENSIVE CARE

Speech-language therapists are part of the peripheral team providing consultative services to periviable infants in the neonatal intensive care unit (NICU). The principles underlying intervention in the NICU are parent-centred care, open and compassionate communication with parents and families, and developmentally appropriate care to infants in order to provide each infant with the best possible developmental outcomes in case of survival. The two main areas of concern for speech-language therapists are to protect and nurture the beginnings of communication development in infants in critical care and intervene when infants experience feeding and swallowing difficulties.

10.2 PREVALENCE OF COMMUNICATION DISORDERS IN PRETERM AND LOW BIRTH WEIGHT INFANTS

While the NICU population of infants may include term infants, the majority have low birth weight and is born preterm. It is estimated that 40% to 65% of infants with low birth weight and born preterm present with developmental delay, including communication and feeding difficulties,[300] and those with very low and extremely low birth weight are at greater risk of developmental disorders and delay.[301] Delayed communication development appears to be the most common symptom of any form of developmental disability in children under three years, affecting approximately 5% to 10% the infant-toddler population. Moreover, recent studies

300 Rossetti LM *Communication Intervention: Birth to Three* (2001) 34.

301 Vanderbilt D *et al* "Preemie neurodevelopment" (2007) *Contemporary Pediatrics* September 2007:1-7.

highlight the range and severity of cognitive, sensory, language, visual-perceptual, attention and learning deficits in very preterm children.[302] According to Lee, Yeatman, Luna and Feldman,[303] not only the severely preterm, but children born late preterm, are also at risk of language and later academic difficulties. As knowledge of the poor developmental outcomes of infants with low birth weight and preterm birth increases, and evidence of early intervention and the potential of brain plasticity become clear, the care that infants receive in the NICU becomes a priority.

10.3 RISK INDICATORS FOR COMMUNICATION DISORDERS (ROSSETTI, 2001)

There is research evidence that the following conditions contribute to speech and language difficulties in all infants, but specifically those in the NICU:

- Perinatal infection
- Birth weight less than 1500g
- Ototoxic medication
- Deviations in sucking or feeding, especially accompanied by NICU stay
- Birth defects
- Blood exchange for hyperbillirubinemia
- Family history of hearing loss
- Family history of speech problems or learning disabilities

10.4 NICU INTERVENTIONS BY SPEECH-LANGUAGE THERAPISTS

Neonatal Interventions should be implemented in collaboration with others who form the core team of professionals in the NICU and with the cooperation of parents of infants. The following neonatal interventions are recommended:

- Kangaroo mother care (KMC) is the most important developmental care approach to implement in the NICU. According to the latest meta-analyses,

302 Allen MC "Neurodevelopmental outcomes of preterm infants" (2008) *Current Opinion in Neurology* 21:123-128.

303 Lee ES *et al* "Specific language and reading skills in school-aged children and adolescents are associated with prematurity after controlling for IQ" (2011) *Neuropsychologia,* 49:906-913.

KMC has a large effect on neonatal mortality and is also effective in reducing morbidity of surviving infants.[304] According to Lawn *et al*[305] this evidence is sufficient to recommend the routine use of KMC in facilities for all stable babies <2000 g at birth. The practice of continuous KMC by parents also enhances mother-infant attachment[306] and the beginnings of communication development in a neonate.[307] Both these processes start before birth but are interrupted by preterm birth and/or neonatal illness.[308]

- Graded sensory stimulation should be provided by the mother according to the three developmental stages of preterm infants, i.e. turning in, coming out and reciprocity stages.[309] When the infant is in the turning in and coming out stages, visual stimuli are kept to a minimum while tactile stimulation is provided by KMC, i.e. skin-to-skin touching, vestibular stimulation when the mother is moving, and auditory stimulation by the mother's voice when she talks and sings softly to the infant. Attempts at eye contact may be met with gaze aversion by the infant during these stages.
- Responsive interaction between mother and infant[310] should be enhanced. The mother is taught to identify stress signs in her infant, to reduce the infant's stress by decreasing sensory stimuli, such as noise, to hold the infant in the KMC position, and only provide stimulation once the infant is regulated and calm. The mother should respond to the infant's subtle cues for readiness to communicate and not to provide intrusive stimulation as cautioned by Klein and Briggs.[311] When the infant is in the reciprocal stage, face-to face interaction is possible. When stress cues, such as gaze aversion, hicupping, sneezing, coughing, stretching arms and pushing feet

304 Lawn JE *et al* "'Kangaroo mother care' to prevent neonatal deaths due to preterm birth complications" (2010) *International Journal of Epidemiology* 39:144-154.

305 *Ibid*.

306 Tessier R *et al* "Kangaroo mother care and the bonding hypothesis" (1998) *Pediatrics* 102(2):e17.

307 Billeaud FP *Communication Disorders in Infants and Toddlers: Assessment and Intervention* (2003) ix.

308 Feldman R "Mother-infant skin-to-skin contact (kangaroo care): theoretical, clinical and empirical aspects" (2004) *Infants and Young Children* 17(2):145-161.

309 Gorski PA *et al* "Stages of behavioral organization in the high-risk neonate: Theoretical and clinical considerations" (1979) *Seminars in Perinatology* 3(1): 61-72.

310 Rossetti LM *Communication Intervention: Birth to Three* (2001) 182.

311 Klein MD and Briggs MH "Observation of Communication Interaction" (1987) *Journal of Childhood Communication Disorders* 10(2):95-106.

are identified, stimulation is reduced and the infant is placed back in the KMC position.

- A family-friendly atmosphere, with reduced light and noise generated by equipment and voices, should be created in all nurseries.
- Families should be provided with information about the nature of their infant's illness, its implications for future health and development, available services once the infant is discharged and their role in the infant's care and development.
- Feeding and swallowing problems in infants in the NICU should be identified and treated as severe difficulties can be prevented.[312]
- As developmental disabilities in infants unfold over time, the potential of early intervention and KMC to promote brain maturation and to ameliorate risks should be recognised.

[312] Arvedson JC and Brodsky L *Pediatric swallowing and feeding: assessment and management* (2002) 304.

CHAPTER 11

(Lurinda Els)

CRITICAL CARE GUIDELINES FOR NEONATES IN SOUTH AFRICA: THE OCCUPATIONAL THERAPY PERSPECTIVE

11.1 INTRODUCTION

Due to the complex developmental and healthcare needs of the preterm infant, a multi-disciplinary team of professionals need to be involved in their care. In this regard the Occupational Therapist has much to contribute in the NICU setting. Using their knowledge of activity analysis and adaptation, they can skillfully enhance the match between the infant and the environment in order to promote optimal development.[313] However, it is very important that the Occupational Therapist working in the NICU has the necessary knowledge and skills in handling the complex needs of high-risk infants and their families. It is also advisable that they have experience and further training in paediatrics.[314]

11.2 OCCUPATIONAL THERAPY APPROACHES WITHIN THE NICU

Occupational Therapy can be applied in the NICU using one of two approaches. Occupational Therapists working part time in the NICU usually make use of the traditional rehabilitation approach which focuses on specific functional problems due to a known or suspected condition, whereas Occupational Therapists working full time in the NICU are seen as "developmental specialists" and have a more expansive role within the NICU environment.[315]

313 Nightlinger K "Developmentally supportive care in the neonatal intensive care unit: An occupational therapists's role" (2011) Neonatal network 30(4):243-248.

314 American Occupational Therapy Association "NICU Knowledge and skills paper" (2006) *The American Journal of Occupational Therapy* 60, 659-668.

315 Diffendal J "OT in the neonatal ICU" (2001) Advance for Occupational Therapy Practitioners 17(14):2-14.

Some intervention techniques that may be employed under the rehabilitation approach include splinting and stretching to maintain or improve passive range of motion. These techniques can also be applied under the developmental approach, but it would form part of a greater intervention strategy.

There are some drawbacks to only having part time Occupational Therapy services within the NICU. Infants might miss out on intervention if not referred specifically, intervention might only be initiated once the infant is already a few days or weeks old, and it becomes more difficult for the Occupational Therapist to build a relationship with the parents as well as the other team members within the NICU.[316]

The full time Occupational Therapist on the other hand would be available to provide timely intervention without other outside responsibilities interfering, and they would be able to assist with indirect services such as family support and joint problem solving.[317] They will also be able to provide developmental support care to all the infants in the unit (and not only those referred to them) through making general adaptations to the environment and through ongoing training of the unit staff members and families.

Although there are logistical and financial barriers to the full time appointment of an Occupational Therapist to the NICU, it seems that it would be ideal to have full time Occupational Therapy services available within the NICU whenever possible.

11.3 OCCUPATIONAL THERAPY INTERVENTIONS CONCERNING THE NEONATE

Apart from the interventions mentioned under the rehabilitation approach, namely splinting and stretching, the Occupational Therapist can also make use of appropriate sensory stimuli to support the development of the neonate.

316 *Ibid*.
317 *Ibid*.

Furthermore, Clark and Schlabach identified two main categories of Occupational Therapy intervention to improve the long term cognitive outcomes of infants, namely developmental interventions and joint attention interventions.[318]

Not only does the Occupational Therapist have much to contribute within the NICU, but she/he also continues to play an important role post discharge and can assist with developmental, physical, cognitive and emotional outcomes.

The rest of this chapter will be dedicated to discussing these different Occupational Therapy interventions according to the literature, and will include recommendations on the application of these interventions within the South African NICU.

11.4 SPLINTING IN THE NICU

Splinting of the neonate is a very delicate undertaking, requiring a skilled practitioner. Hand dysfunction within this population is seen frequently, and can be a result of upper or lower motor neuron lesions, fractures, dislocations or genetic anomalies.[319]

Although a date reference, the article by Anderson and Anderson (1988) on hand splinting of the neonate still seems to be one of the guiding documents when it comes to splinting in the NICU, and it still forms the base of some modern guidelines on splinting of the neonate.[320]

It is important to remember that splinting cannot be used as a stand-alone treatment technique – it is only one part of the hand therapy programme, and splinting might not always be indicated.

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318 Clark GJ and Schlabach TL "Systematic review of occupational therapy inteventions to improve cognitive development in childrens ages birth – 5 years" (2013) *The American Journal of Occupational Therapy* 67(4):425-430.

319 Anderson LJ and Anderson JM "NICU Knowledge and skills paper" (2006) *The American Journal of Occupational Therapy* 60, 659-668; Granhaug KB in Henderson A and Pehoski (eds) "Splinting the upper extremity of a child" (2006) *Hand Function in the Child: Foundations for Remediation* 401-427.

320 Granhaug KB in Henderson A and Pehoski (eds) (2006) 401-427.

There are six indications for splinting of the neonate in the NICU:[321]

1. If the neonate has a progressive hand deformity which cannot be managed by a hand treatment programme alone, splinting would be indicated;
2. If the amount of time needed for successful performance of the hand treatment programme exceeds the amount of time available to staff in the NICU, splinting would be indicated;
3. If the infant is medically unstable and would not be able to tolerate the excessive and repeated handling necessary for the successful performance of the hand treatment programme, splinting would be indicated;
4. If parents or family members are unwilling or hesitant to participate in the hand treatment programme, splinting would be indicated;
5. If the hand treatment programme is too complex for the parents and other staff members in the NICU to master, splinting would be indicated;
6. If the parents or other staff members are fearful of inflicting further damage to the child by participating in the hand treatment programme, and subsequently decide not to participate, splinting would be indicated.

If the Occupational Therapist decides on incorporating splinting in the hand treatment programme, there are a few points to take into consideration. Firstly, material selection is very important. As the neonate's skin is much more sensitive than that of the adult or even the older child, they are more prone to burning. As such, a low temperature thermoplastic material is best to use in the NICU. "Growth and changes in joint alignment (also) necessitate frequent adjustments (to the splint)", thus the material should be able to withstand frequent reheating and remodeling.[322]

The material should also be lightweight, so as to permit maximum functional mobility of the limb. Thinning of the material can produce a lighter splint. Thermoplastic is also not the only material to take into consideration. Sometimes

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321 Anderson LJ and Anderson JM "Hand splinting for infants in the intensive care and special care nurseries" (1988) *The American Journal of Occupational Therapy* 42(2), 222- 226.

322 Anderson LJ and Anderson JM (1988) 225.

the desired effect can be achieved using soft splinting materials such as neoprene, or even non-splinting materials such as sponge, taping and elastonet. Secondly, great care should be taken to avoid pressure areas on the splint. The therapist must ensure that there are no sharp edges on the splint, and be vigilant for any signs of skin irritation once the infant is wearing the splint. To prevent the child from inadvertently hurting himself with the splint, the hand and splint can be covered with a baby sock or something similar.[323]

Thirdly, correct alignment of the splint is of paramount importance. Any malalignment can cause severe long term problems, and should be corrected immediately.

Lastly, attention should be given to the correct use of straps. If a strap is pulled too tightly, edema is very likely to occur. It is also better to use wider straps as opposed to thinner straps to spread out the pressure over a larger area. The strap can even be as wide as the length of the splint itself. It should also be easily removable for cleaning or replacement.[324]

Once the splint has been manufactured and it has been applied to the infant, it is recommended that hourly skin checks be performed for the first four hours of wearing the splint. Thereafter, the schedule would be four hours on, one hour off, with hand exercises being performed during the times that the splint is removed.[325]

Splinting can be a very helpful addition to a hand treatment programme if used correctly and should form part of the therapeutic services available within the NICU.

11.5 DEVELOPMENTAL INTERVENTIONS

All babies are born into a foreign sensory environment. The sensory world of the womb is characterised by neutral warmth, deep pressure with no light touch,

323 Anderson LJ and Anderson JM (1988) 222-226; Granhaug KB (2006) 401-427.
324 Anderson LJ and Anderson JM (1988) 222-226.
325 Anderson LJ and Anderson JM (1988) 222- 226; Granhaug KB (2006) 401-427.

muted sound and light, constant vestibular input, decreased effect of gravity and the sweet smells and tastes of the amniotic fluid.[326]

Compare this with the harsh sensory environment of the Neonatal Intensive Care Unit, and combine it with the fact that most babies in these units have either premature systems or other conditions impeding their ability to cope. Therefore it is not difficult to see that it would be beneficial to these neonates if some measures were to be taken to support and protect their development while in NICU.

According to the literature there are several ways to achieve this.[327] This includes controlling the external sensory stimuli such as light and sound, altering the positioning and handling of the infants, clustering nursing care activities, paying attention to pain and analgesia and promoting Kangaroo Mother Care, breastfeeding and family involvement. Each of these will be discussed in more detail in this chapter.

These measures are collectively called developmental care, developmental support care or neurodevelopmental care. It is defined by Nair *et al* as "a broad category of interventions designed to minimize the stress of the NICU environment."[328]

The NIDCAP (Neonatal Individualized Developmental Care and Assessment Program) developed by H. Als[329] is an organised system that can be used to design individual developmental care programmes for each neonate in NICU. This could be described as current best practice in developmental care in the NICU. However, in order to make use of this, the staff in the unit should be trained and

326 Faure M and Richardson A (2010) *Baby Sense.*

327 Aucott S *et al* "Neurodevelopmental care in the NICU" (2002) *Mental Retardation and Developmental Disabilities Research Reviews* 8, 298-308; Nair MNG *et al* "NICU environment: Can we be ignorant" (2003) *Medical Journal Armed Forces India* 59, 93-95; Symington and Pinelli cited in Legendre V *et al* "The evolving practice of developmental care in the neonatal unit: A systematic review" (2011) *Physical and Occupational Therapy in Pediatrics* 31(3):315-338.

328 Nair MNG *et al* (2003) 94.

329 Als H "Program guide: Newborn individualized defelopmental care and assessment program (NIDCAP). An educational training program for health care professionals" (1986, revised 2015) *NIDCAP Federation International*.

certified. As training is currently unavailable in South Africa and is very expensive, this is not a viable option for South African NICU's as a rule. However, there are still general things that could be done in the NICU to make it a more developmentally supportive environment.

11.5.1 External sensory stimuli

The timeous and controlled introduction of sensory stimuli is very important to the development of the different sensory systems of the neonate. Stimuli should not be introduced before the system is ready, as maturation cannot be forced or accelerated, but must merely be supported. Stimulation must be introduced in the order of sensory system development, that order being: tactile (see par 11.5.1.5.3), proprioceptive (see par 11.5.1.5.3), vestibular, olfactory and gustatory (see par 11.5.1.2), auditory (see par 11.5.1.3) and lastly visual.[330]

11.5.1.1 Vestibular input

This occurs naturally when the parents hold and rock their infant.[331] Due to the immaturity of the system, only one type of vestibular input should be presented at a time (e.g. rocking side-to-side or up-and-down, but not to combine the two movements in one).

11.5.1.2 Olfactory and gustatory input

These experiences mostly center on feeding.[332]

The neonate's sensitivity to odours also needs to be taken into account in the NICU environment. Alcoholic vapours and chlorine release irritation, a trigeminal component of odour. Preterm neonates are sensitive to these trigeminal

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330 Bader L "Intervention techniques for OTs in the NICU" (2010) PT Practice 15(2). [Retrieved from http://www.otptinthenicu.com/about.htm]

331 *Ibid*.

332 *Ibid*. See par 11.5.1.5.6 below for a full discussion.

components, and it has been found that even in low concentrations, these odours can cause apnoea and lowered respiratory rate in these infants.[333]

Most noxious odours arise from substances used in the routine care of these infants, and especially the use of alcohol hand rub for hygienic reasons cannot be debated. However, Kuhn makes a few suggestions to lessen the effect:

Alcohol hand rub or foam must be allowed to dry completely before handling the infant. A product with a shorter drying time can also be used. Applications of lotion, soap or detergents to the newborn's skin should be kept to a minimum, and when it is used, the least odorous product should be used. The use of other noxious odorous products should always be carefully considered, for example the use of adhesive removals in the infant's vicinity, as well as the routine use of lubricants on tubing used for the infant's care. The benefits of using these products should always be weighed against the risks of the trigeminal stimuli released by them. Lastly, increased ventilation of the incubator can diminish the intensity and the duration of the exposure to certain smells.

11.5.1.3 Auditory input

As the auditory system in the preterm neonate is very sensitive, auditory stimulation in the NICU is mostly avoided.[334] A neonate's sense of hearing is fully developed by 28 weeks,[335] and this is exactly the reason why sound levels in the NICU should be closely monitored to prevent any damage or hearing loss. Parents and staff members should use soft voices when talking to the infant and always be mindful of the sound levels within the NICU.[336]

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333 Kuhn P *et al* "Exploring the olfactory environment of premature newborns: A French survey of health care and cleaning porductes usesd in neonatal units" (2010) *Acta Paediatrica* 110(3), 337.

334 Bader L "Intervention techniques for OTs in the NICU" (2010) PT Practice 15(2). [Retrieved from http://www.otptinthenicu.com/about.htm].

335 Faure M and Richardson A *Baby sense* (2010).Please provide page numbers.

336 See chapter 9 above for more details and recommendations.

11.5.1.4 Visual input

As vision is the most immature sense at birth,[337] it is important to protect this sense in the NICU environment. Visual stimulation must be delayed until the infant can tolerate other forms of sensory input and is physiologically stable. Human faces (especially that of the parent) is sometimes all the visual stimulation the infant needs, and visual stimuli should not be placed in such a way that the infant cannot escape it.[338]

Exposure to light must also be controlled, as it has been shown to affect the growth,[339] cortisol production[340] and oral feeding[341] in infants in the NICU environment.

Being a stress hormone, increased levels of cortisol has been shown to be hazardous to brain development and exposure to bright light has been shown to increase stress levels in infants, as observed by increases in bradycardia, activity levels and poor sleeping patterns.[342] However, some NICU's still favour bright overhead lighting in order to increase visibility during the care of these infants.

Some NICU's have started making use of constant near darkness in order to replicate the womb environment as well as to attempt decreasing stress in the infants. However, Coventry and Jamison state that: "Lack of light impedes growth because less cortisol is produced."[343] Furthermore, it has been found that when levels of this hormone in premature infants are too low, it could be linked to

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337 Faure M and Richardson A *Baby sense* (2010)Please provide page numbers; Eliot L *What's going on in there: How the brain and mind develop in the first five years of life* (2000).Please provide page numbers.

338 Bader L "Intervention techniques for OTs in the NICU" (2010) PT Practice 15(2). [Retrieved from http://www.otptinthenicu.com/about.htm]

339 Brandon *et al* "Preterm infants born at less than 31 weeks' gestation have improved growth in culced light compared with continuous near darkness" (2002) *The Journal of Pediatrics* 140(2),192-199.

340 Coventry M and Jameson A "Implementation of cucled lighting in a single-room neonatal ICU" (2009) *Critical Care Nurse* 29(1):95-96.

341 Pickler RH *et al* "Effects of the neonatal intensive care unit environment on preterm infant oral feeding" (2013) Research and Reports in Neonatology 3,15-20.

342 Brandon *et a*l (2003) 192-199.

343 Coventry M and Jameson A (2009) 96.

mortality, low blood pressure, increased severity of illness and bronchopulmonary dysplasia.[344]

In a study conducted by Brandon *et al*[345] it was found that cycled lighting had positive effects on the growth of neonates in NICU. Furthermore cycled lighting awards the neonates the opportunity to develop their circadian rhythms – internal body rhythms that synchronize physiological processes, sleep-wake patterns and hormone production with the 24 hour dark-light cycle.

In abovementioned study they made use of cycled lighting in an 11 hours on, 11 hours off pattern, with one hour allowed for shift changes where the light would vary. They describe a light level of 200 – 225 lux for daytime hours, which is lower than the 400 – 900 lux of previous research, and 5 – 10 lux for the night-time hours.

Looking at the evidence, it is therefore suggested that cycled lighting be implemented in NICU's in South Africa, to assist with the general wellbeing and development of these neonates. It is suggested that the levels and cycling of light be used as in the Brandon et al. study, until further research can be done.

11.5.1.5 Positioning and handling

11.5.1.5.1 Positioning and pressure care

Evidence supports the Kangaroo position as the preferred position of care for preterm and low-birth-weight infants.[346] However, if a neonate is being cared for in an incubator, or if Intermittent Kangaroo Mother Care is being practised, the following positioning guidelines are recommended.

The positioning of neonates in the NICU has been the subject of debate for a number of years, partly due to conflicting advantages and disadvantages of the

344 Watterberg *et al* (2007) 120(1):40-48.
345 Brandon *et a*l (2003) 192-199.
346 Nyqvist K *et al* "State of the art and recommendations, Kangaroo Motheh Care: Application in a high-tech environment" (2010) *Acta Paediatrica* 99(6),812,-819. See par 11.5.1.5.5 below for a detailed discussion.

prone and supine position.[347] It has been found that the prone position in neonates decreases apnoea and increases arterial oxygen saturation[348] as well as increasing periods of quiet sleep, which further contributes to higher oxygen saturation.[349]

However, the prone position without adequate support can lead to increased rotation and hyperextension of the neck to open the airway. This head position may lead to decreased blood flow to the brainstem via the vertebral artery[350] which can lead to further neurological complications. Furthermore it has been found that postural deformities and delayed muscle development were more prevalent in premature infants placed in the prone position.[351]

Placing a preterm infant in the supine position without the proper supports can cause long term damage to joints as well as muscle development. Gravity pulls the hips into lateral rotation, causing a splayed "frog-like" position. It is difficult for the infant to bring his hands to his face against gravity, and the head and neck might also fall back into hyperextension.

There are also risks involved when an infant is kept in one position for a prolonged period of time. Head moulding can occur due to prolonged time spent in supine or in side-lying, leading to occipital flattening or long narrow heads respectively.[352] Furthermore, acutely ill and immobilised neonates are at risk of pressure sores[353] and their positioning should take this into account.

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347 Eichler F *et al* "Position dependent changes of cerebral blood flow velocities in premature infants" (2001) *European Journal of Pediatrics* 160:633-639.

348 Eichler F *et al* (2001) 633-639; Picheansathian W *et al* "Positioning of preterm infants for optimal physiological development "A systematic review" (2009) *Briggs Institute Library of Systematic Reviews* 7(7):224-259.

349 Chang Y *et al* "Effects of prone and supine positions on sleep state and stress responses in mechanically ventilated preterm infants during the first postnatal week" (2002) J*ournal of Advanced Nursing* 40(2):161-169.

350 Eichler F *et al* (2001) 633-639.

351 Picheansathian W *et al* (2009) 224-259.

352 Bronfin DR "Misshapen heads in babies: Position or pathology?" (2001) *The Ochsner Journal 3,*191-199.

353 Baharestani MM and Ratliff CR "Pressure ulcers in neonates and children and NPUAP white paper" (2007) *Advances in Skin and Wound Care* 20(4):208-220.

Pressure care in the NICU is a very important aspect of care. As opposed to the sacrum in adults, the occiput is the most common area for pressure ulcers in the paediatric population. Furthermore, it has been found that more than 50% of pressure sores in this population are caused by devices and equipment.[354]

Another aspect to consider in positioning is physiological flexion and the use of boundaries. Preterm babies do not exhibit the muscle tone or strength to maintain this position against gravity yet. Physiological flexion has been found to support self-regulation, growth, physiological stability as well as the development of correct posture and movement.[355] The use of boundaries (or nesting as it is otherwise known) can help to facilitate physiological flexion in the newborn infant. By providing boundaries, the effect of gravity on the limbs and joints as discussed earlier can also be minimised.

In light of the literature, the following suggestions are made regarding the positioning and pressure care of neonates in NICU:

Upon admission, each neonate should receive a thorough skin assessment, including assessing for pressure risk areas. There are several pressure ulcer risk assessment tools, of which four are designed for use on neonates: The Bedi, The Neonatal Skin Risk Assessment Tool (NSRAS), The Pediatric Waterlow and the Glamorgan. Of these, the NSRAS has been developed to use on preterm infants of 26 to 40 weeks gestational age.[356] The skin should ideally be assessed daily, and special attention should be given to high risk areas, such as under the occiput and under medical devices, splints and CPAP masks. If a pressure area develops, this should be documented and reported, and further measures to relieve the pressure on this area should be taken.

The standard of care for adults is changing position every two hours. However, such frequent position changes of neonates could result in physiological instability

354 *Ibid*.
355 Lubbe W *Prematurity: Adjusting Your Dream* (2008).Page numbers?
356 Baharestani MM and Ratliff CR (2007) 208-220.

presenting as apnoea, tachycardia, bradycardia and slower oxygenation recovery time.[357]

Thus, it is suggested that pressure care mattresses be used in concurrence with position changes every four hours.[358] Viscoelastic foam mattresses proved to assist infants in maintaining their body temperature more effectively as well as aiding more in normal skull development as opposed to gel mattresses.[359] It is important to evaluate the pressure care mattress for efficacy in the neonate population before use. For infants under 32 weeks' gestation age, it is suggested that further measures be taken routinely, by placing pressure care materials such as sheepskin or gel pads under the joints, ears and occiput.[360]

When placing the infant in any position (prone, supine or side-lying), it is important to use supports and boundaries. Lubbe describes the use of boundaries and supports for all positions and suggests the following: [361]

In prone, the infant should be placed on a tummy roll – the thickness of which should be the same as the length of the baby's upper leg from the hip joint to the knee. The roll should be positioned from the umbilical cord to the head. By doing this the baby is supported in a flexed position. Furthermore, lateral rotation of the hips and rotation and hyperextension of the neck can be prevented. Position the head in neutral facing the side and place the hand on that side close to the mouth. Provide a strong yet flexible boundary around the baby's body.

In supine the baby's head should be positioned in the midline and in neutral to maintain an open airway. Boundaries should be used to support physiological flexion of the hips and knees in midline. Foot bracing against a firm yet flexible boundary is very important. The shoulders should be slightly rounded forward to support the hands in the midline near the face and an additional shoulder roll

357 *Ibid*.
358 *Ibid*.
359 De Raeve P *et al* "Two mattresses for neonates compared for cost and quality of nursing care" (2001) *Connect – Critical Care Nursing in Europe* 1(1):5-10.
360 Lund C "Prevention and management of infant skin breakdown" (1999) *The Nursing Clinics of North America* 34(4):907-920.
361 Lubbe W (2008) 92-94.

placed underneath the boundary can assist with this. Be careful not to place the shoulder roll underneath the neck. The shoulder roll should be as wide as the baby's wrist and no thicker than the baby's arm. Lastly, the neonate will always benefit from a boundary at the head as well.

The side–lying position is beneficial as gravity decreases lateral rotation of the hips and the infant finds it easier to reach his face with his hands. In this position body containment is also very important and the hips and shoulders should be slightly rounded forward. The hips and knees should be flexed with the feet bracing against the boundaries. The back should be slightly rounded with the ear, shoulder and hip in a straight line.

Nappy size is a sometime neglected aspect that also influences the neonate's hip joint position. A nappy that is too big will bunch between the legs and cause lateral rotation of the hips. It is therefore important to use the correct size nappy at all times.

11.5.1.5.2 Handling

When handling the neonate, it is important to note that their immature sensory systems could lead to light touch being perceived as threatening and painful, and firm touch should rather be used. It is also important to note that the infant's vestibular system might still be underdeveloped. Therefore, when picking up the baby, contain the limbs and bend down towards the baby in order to minimise the amount of time he is in free space.

It is always important to be mindful of the quantity and quality of handling the neonate is exposed to. However, the importance of loving, appropriate touch cannot be underestimated. Containment holds and static proprioceptive input can be used with the medically fragile and very young preterm infant as tactile stimulation, prior to adding infant massage and kinaesthetic movement.[362]

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[362] Bader L "Intervention techniques for OTs in the NICU" (2010) *OT Practice* 15(2). [Retrieved from http://www.otptinthenicy.com/about.htm]

11.5.1.5.3 Infant massage

Infant massage has many documented benefits for preterm infants.[363] Numerous studies have shown that infant massage using moderate pressure, combined with passive movements of the extremities led to increased weight gain, increased bone mineral density and shortened hospital stay in medically stable preterm infants.[364] The massage protocol employed in most of these studies is described below: [365]

The massage session of 15 minutes is broken down into three segments of five minutes each. During the first and last five minutes, the infant receives tactile input, and during the middle five minute segment, the infant receives kinaesthetic input.

For the tactile input, the infant is placed in prone, and the caregiver/health professional uses their warmed palms to provide the massage. It consists of five periods of one minute each, with each minute comprising of 12 strokes of five seconds each (please see table below for more detail).

For the kinaesthetic input, the infant is placed in supine to perform passive flexion/extension movements of the limbs. It similarly consists of five periods of one minute each, comprising of six passive movements for 10 seconds per body part (please see table below for more detail).

	First segment Tactile input Prone 12 strokes of 5 seconds each	Second segment Kinaesthetic input Supine 6 movements of 10 seconds each	Last segment Tactile input Prone 12 strokes of 5 seconds each
1	From the top of the head to the neck and back again	One arm	From the top of the head to the neck and back again
2	From the neck across the	Other arm	From the neck across the

363 See also chapter 7 par 7.3.4 above.

364 Field T *et al* "Preterm infant massage therapy research: A review" (2010) *Infant behaviour and development* 33(2) 115-124.

365 Field T *et al* "Stimulation programs for preterm infants" (2004) *Social Policy Report* 5.

	shoulders and back again		shoulders and back again
3	From the upper back to the waist and back again	One leg	From the upper back to the waist and back again
4	From the hip to the foot and back again on both legs	Other leg	From the hip to the foot and back again on both legs
5	From the shoulder to the hand and back again on both arms	Both legs together	From the shoulder to the hand and back again on both arms

Massage therapy procedure adapted from Field *et al*.[366]

The protocols in these studies indicated massage intervention three times daily for between five and 10 days. Subsequently, 5 days proved to be an adequate time period for significant weight gain.[367]

To be eligible to receive massage intervention, an infant must firstly be medically stable and "out of medical jeopardy".[368] Secondly, the weight of the infant at commencement of the intervention must be taken into consideration. It has been found that infants only gain weight if the massage intervention was started at a weight between 1100 grams and 1300 grams. Infants weighing more than 1700 grams at the beginning of the intervention did not gain any weight due to the massage.[369] T Field and her team currently only recruit infants weighing 1500 grams or less for commencement of massage intervention.[370] Thirdly, the infant must be able to tolerate containment holds and static proprioceptive input prior to commencing massage intervention.[371]

Using moderate pressure (as opposed to light pressure) is of critical importance, as light touch can be perceived as threatening to the immature sensory system. Furthermore, stimulation of pressure receptors within the skin have been linked

366 *Ibid*.
367 Field T *et al* (2004) 1-19.
368 *Idem* 5.
369 *Idem* 1-19. Hernandez-Reif *et al* (2001) is cited in this work by Field *et al*.
370 Field T, personal communication, November 13, 2015.
371 Bader L (2010).

with the increased vagal activity which is believed to be an underlying mechanism for the weight gain effects of massage therapy in preterm infants (Field *et al*, 2010).[372]

Studies have shown that massage using oil increased weight gain even more than massage alone. Some studies made use of organic oils such as coconut and safflower oils.[373] However, the current protocol being implemented by T. Field and her team make use of *Johnson & Johnson* baby oil, as it is hypoallergenic and is not absorbed by the skin after some of the babies had allergic reactions to the organic oils.[374]

Even though the Cochrane review on massage for promoting growth and development of preterm and/or low birth-weight infants found weak evidence to support the benefit of massage for preterm infants,[375] it is important to note that no distinction was made between protocols making use of light touch massage and moderate pressure massage in this review.[376] In contrast to these findings, there is a growing body of evidence supporting the benefits of moderate pressure massage for preterm infants. Furthermore, the Cochrane review found no harmful effects of preterm infant massage.

Therefore, it is suggested that the massage protocol as described above be implemented in NICU's in South Africa to promote weight gain and thus shorten hospital stay. Furthermore it is suggested that the massage protocol be taught to the infant's mother where possible, as the massage has been found to be just as effective when administered by the mother.[377] Mothers performing massage on their own preterm infants also experience relief of depression symptoms.[378] By

372 Field *et al* (2010) 115-214.
373 Sankaranarayanan et al., 2005; Solanki et al., 2005Please provide full details.
374 Field T, personal communication, November 16, 2015.
375 Vickers A *et al* "Massage for promoting growth and development of preterm and/or low birth-weight infants" (2004) *Cochrane database of systematic reviews* Issue 2.
376 Field T, personal communication, November 13, 2015.
377 Goldstein Ferber S *et al* "Massage therapy by mothers and trained professionals enhances weight gain in preterm infants" (2002) *Early Human Development* 67(1-2),37-45.
378 Feijó L et al "Mothers' depressed mood and anxiety levels are reduced after massaging their preterm infants" (2006) *Infant Behaviour and Development* 29(3),476-480.

having the mother perform the massage, it also frees up the time of the health care professionals, thus not adding to their workload.

11.5.1.5.4 Pain management

Management of pain in the neonate is another aspect to consider when it comes to developmental support care. Nociceptive pathways develop as early as 23 weeks' gestational age, with the "descending neurotransmitters that modulate pain only developing later postnatally".[379] A premature infant could therefore actually be more sensitive to pain than an adult. Furthermore, studies have shown that greater cumulative exposure to painful experiences in physiologically immature infants lead to cortisol levels being dampened while still in hospital, only to be elevated later in life, leading to hyperalgesia and increased sensitivity to pain.[380] It is therefore important to make use of appropriate pharmacological and/or non-pharmacological means to lessen the pain of these neonates in general and during procedures. Clustering of nursing activities could also be utilised to minimise the amount of time the infant is exposed to threatening touch.

Non-pharmacological pain management

The Cochrane review on non-pharmacological management of infant and young child procedural pain[381] reviewed the efficacy of interventions in addressing pain related behaviours in infants and young children. The review distinguished between three age groups – preterm infants (36 weeks' gestation or less), neonates (37 weeks' gestation until one month corrected age) and older infants (one month until 36 months corrected age). Each intervention was rated on a scale of 1-4 on its effectiveness in addressing pain related behaviours for all three age groups:

1. Sufficient evidence supports its efficacy
2. Limited evidence suggests its efficacy
3. Limited evidence suggests its inefficacy

379 Aucott et al "Neurodevelopmental care in the NICU" (2002) *Mental Retardation and Developmental Disabilities Research Reviews* 8, 304.

380 Grunau et al., 2006Author please provide full details.

381 Pillay Riddell RR *et al* "Non-pharmacological management of infant and young child procedural pain (review)" (2012) *Evidence Based Child Health: A Cochrane Review Journal* 7(6), 1905-2121.

4. Sufficient evidence supports its inefficacy

According to this review, the following interventions are suggested for non-pharmacological pain management (scale rating included):

Preterm infants:	Facilitated tucking/swaddling (1)
	Non-nutritive sucking (1)
	Kangaroo care (1)
	Environment modifications (2)
Neonates:	Non-nutritive sucking (1)
	Rocking/holding (1)
	Facilitated tucking/swaddling (2)
Older infants:	Non-nutritive sucking (2)
	Video distraction (2)

Facilitated tucking refers to a caregiver containing the infant's body by placing their hands on the child's head and lower limbs, maintaining a flexed body position. Swaddling involves securely wrapping the infant in a blanket, preventing excessive limb movement.

Non-nutritive sucking is part of an infant's natural repertoire of oral movements, and occurs in response to non-nutritive presences in the mouth. This can be elicited with a pacifier, the infant's own fingers, the mom's finger or an empty breast. The use of pacifiers in breastfeeding infants is highly controversial due to the possibility of nipple confusion, and can even currently affect a hospital's BFHI (Baby Friendly Hospital Initiative) status when used in NICU.[382]

Kangaroo care involves placing the infant on the caregiver's bare chest prior to or during a painful procedure.[383] It was not found effective for pain management in the neonate group in this review. However, due to its significant effect on pain behaviour in preterm infants, the review suggested that further research using longer exposure to kangaroo care prior to the painful stimulus (10 minutes or longer) should be explored.

[382] See par 11.5.1.5.5 below for a detailed discussion.
[383] See par 11.5.1.5.5 below for more details.

Environment modifications refer to changing the sensory aspects of the NICU environment such as lighting and noise levels as well as clustering of nursing activities.

Rocking/holding is when the infant is held and/or moved gently up and down and/or side to side.

Video distraction involves diverting the infant's attention away from the painful stimuli through the use of audio-visual means.

This review focused mainly on the ability of the intervention to modify pain related behaviours in the infant, and did not include physiological measures of pain. In a separate Cochrane review on breastfeeding or breast milk for procedural pain in neonates[384] it was found that breastfeeding was associated with a decrease in duration of crying, percentage of time crying and changes in heart rate following a single painful procedure.

Breastfeeding was found to be less effective than higher concentrations of oral sucrose/glucose for short term pain relief. However, long term use of sucrose solutions have been linked to lower scores on motor development, alertness and orientation, as well as increased neuro-biological risk scores at later ages in certain populations.[385]

Administering of oral sucrose prior to or during a painful procedure is seen as standard care in numerous NICU's. However, recent evidence is casting doubt on the efficacy and safety of sucrose as an analgesic.[386]

Electroencephalographic studies have shown that the amount of nociceptive-specific brain activity in infants receiving sucrose was not reduced during a painful procedure, even though they were less likely to have a facial response to the pain

384 Shah PS *et a*l "Breastfeeding or breast milk for procedural pain in neonates (review)" (2006) *Cochrane Database of Systematic Reviews* (3).

385 Johnston CC *et al* "Routine sucrose analgesia during the first week of life in neonates younger than 31 weeks postconceptional age" (2002) *Pediatrics* 523-528.

386 Wilkinson DJC *et al* "Sugaring the pill: Ethics and uncertainties in the use of sucrose for newborn infants" (2012) *Archives of Pediatrics and Adolescent Medicine* 629-633.

and they received lower pain scores. The spinal reflex withdrawal was also not affected. Wilkinson *et al* theorises that there are three possible reasons for this discrepancy.[387]

The first possibility is that the sensory aspects of pain and the affective/negative psychological aspects of pain are mediated by different neural pathways. This could cause the infant to still experience the perception of pain, but to be less distressed by it – leading to a reduction in pain related behaviour. The second possibility is that sucrose acts as a sedative, rather than an analgesic agent, and the third possibility is that sucrose acts as a compensation or distraction during the painful event. "Distraction or compensation might lead to reduced behavioral responses without affecting cortical nociceptive or spinal reflex activity".[388]

This could of course be true of any of the interventions described earlier that proved effective in reducing pain related behaviours. However, oral sucrose is the only pain management intervention reviewed here with questionable long term effects. Sucrose treated infants seem to be just as likely to experience hyperalgesia and increased sensitivity to pain at a later age as infants treated with a placebo,[389] thus oral sucrose lacks long term benefits. Furthermore there are concerns surrounding the effect of sucrose use on attention and motor development,[390] as well as the infant's long term health based on the effect of early nutrition on developmental programming.[391] In light of the newest evidence, it seems that the risks outweigh the possible benefits of oral sucrose administration to neonates in NICU.

It is therefore suggested that the interventions as described in the Cochrane review on non-pharmacological management of infant and young child procedural pain and as set out at the beginning of this section be adopted as pain management strategies in the South African NICU, with the addition of

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387 *Idem* 631.

388 *Ibid*.

389 Taddio A *et al* "Influence of repeated painful procedures and sucrose analgesia in the defelopment of hyperalgesia in newborn infants" (2009) *Pain* 144(1-2):43-48.

390 Holsti L and Grunau RE "Considerations for using sucrose to reduce procedural pain in preterm infants" (2010) *Pediatrics* 125(5):1042-1047.

391 Wilkinson DJC (2012) cited in Wiedmeier *et al* (2012). Page number?

breastfeeding or administering of expressed breast milk where the infant is able to handle oral feeds.

11.5.1.5.5 Kangaroo care

Kangaroo care, or Kangaroo mother care (KMC) as it is more commonly known, forms a vital part of the developmental support practices to be implemented in the NICU as it serves many purposes for both the infant and the mother.

Since its origination in 1979 in Bogotá, Colombia,[392] KMC has undergone rigorous study, proving its effectiveness as a care model for preterm and low-birth-weight infants.[393] It should not be regarded as inferior to traditional care, but rather as an evidence-based, scientific intervention with many behavioural and psychosocial benefits.[394]

The benefits of skin-to-skin contact have been explored in multiple studies and reviews[395] and include:

- Infant warming and thermoregulation
- Reduced neonatal mortality rates
- Positive developmental outcomes
- Positive effects on breastfeeding
- Reduced bradychardic events
- Reduced incidences of hospital-acquired infections

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392 Venancio SI *et al* "Kangaroo mother care: Scientific evidence and impact on breastfeeding" (2004) *Jornal de Pediatria* 80(5):173-180.

393 Nyqvist KH *et al* "Towards universal Kangaroo Mother Care: Recommendations and report from the first European conference and seventh workshop on Kangaroo Mother Care" (2010) Acta Paediatrica 99(6):820-826; Ludington-Hoe SM *et al* "A clinical guide for implementation of Kangaroo Care with premature infants of 30 or more weeks' postmenstrual age" (2008) *Advances in Neonatal Care* 8(3S):3-23.

394 Bergh A *et al* "Education and training in the implementation of kangaroo mother care" (2012) *South African Journal of Child Health* 6(2):35-45; Nyqvist KH *et al* "Towards universal Kangaroo Mother Care: Recommendations and report from the first European conference and seventh international workshop on Kangaroo Mother Care (2010) *Acta Paediatrica* 99(6):820-826; Ludingon-Hoe SM *et al* "A clinical guideline for implementation of Kagaroo Care with premature infants of 30 or more weeks' postmenstrual age" (2008) *Advances in Neonatal Care* 8(3S):3-23.

395 Ludington-Hoe SM *et al* (2008) 3-23; Venancio SI and De Almeida H "Kangaroo Mother Care: Scientific evidences and impact on breastfeeding" (2004) *Jornal de Pediatria* 80(5):173-180.

- Improved sleep integrity of the infant
- Reduced crying during painful procedures
- Improved parental adaptation to preterm birth

According to the WHO guidelines on Kangaroo Mother Care the key features of KMC include:

- early, continuous and prolonged skin-to-skin contact between the mother and the baby;
- exclusive breastfeeding (ideally);
- it is initiated in hospital and can be continued at home;
- small babies can be discharged early;
- mothers at home require adequate support and follow-up;
- it is a gentle, effective method that avoids the agitation routinely experienced in a busy ward with preterm infants.[396]

These align with the three original components of KMC: use of kangaroo position (KP); exclusive breastfeeding (ideally); and early discharge in KP with strict follow up.[397]

Kangaroo position

The Kangaroo position involves continuous skin-to-skin contact with the mother/caregiver, with the infant placed on the mother's chest in a vertical position under her clothes, wearing only a diaper, hat and socks. The infant should be secured in this position using a cloth band or binder. Unless the hospital or institution already has a device it routinely uses, it is suggested that the Thari (wrap) designed by Dr. Elise van Rooyen[398] be used.

396 World Health Organization, Dept. of Reproductive Health and Research (2003) 2.
397 Nyqvist KH *et al* (2010) 820-826.
398 van Rooyen E "Instructions to tie the Kalafong KMC Thari (Wrap)" (2011) Retrieved January 13, 2016 from http://archivedpublicwebsite.up.ac.za/sitefiles/file/45/1335/877/Thari%20Instructions%20&%20New%20KMC%20wrap%20pattern%20May%202011.pdf

Initiation and duration

Current recommendations state that KMC should be initiated at birth whenever possible as opposed to the original practice of initiating it only after the infant has been medically stabilised.[399] Two separate studies performed in South Africa illustrated that KMC led to improved survival rates among infants, and that it is superior to conventional incubator care when stabilising non-critically ill infants. It is also important to note that ventilator/CPAP treatment does not prevent an infant from receiving KMC, and he can be placed in the kangaroo position as soon as he is stabilised.[400]

This correlates with the view that mother-infant separation should be avoided as far as possible, especially directly after birth, when it can lead to stress for both mother and infant and can adversely affect physiological stability, co-regulation and psycho emotional development of the infant.[401] This view is also supported by the "Baby friendly hospital initiative" launched by WHO and UNICEF in 1991 which suggests rooming in (allowing the mother and infant to remain together 24 hours a day) as part of their "Ten steps to successful breastfeeding".[402]

According to Nyqvist *et al*,[403] there are two modalities of KMC practice, namely continuous KMC (C-KMC) and intermittent KMC (I-KMC), which are used depending on the circumstances of the mother and infant. C-KMC refers to 24 hour a day direct skin contact between mother and infant, maintaining the infant's body temperature and providing for all nutritional and stimulational needs. I-KMC refers to short periods of skin-to skin care, once or more than once a day with the aims including improved bonding and breastfeeding.
Current international recommendations promote the use of C-KMC whenever possible as part of routine newborn care. However, when circumstances do not permit this, I-KMC can precede C-KMC, as long as a session lasts for at least an

399 Nyqvist KH *et al* (2010) 820-826.
400 Nyqvist KH et al "State of the art and recommendations, Kangaroo Mother Care: Application in a hig-tech environment" (2010) 812-819. Please follow the "Procedure for ventilated kangaroo care" as set out in Ludington-Hoe SM *et al* (2008) 18-19.
401 Nyqvist KH *et al* (2010) 820-826; Venancio SI and De Almeida (2004) 173-180.
402 UNICEF/WHO 2009. Please see below for more details.
403 Nyqvist KH *et al* (2010) 820-826.

hour at a time, as it can be stressful for the infant to transfer in and out of the kangaroo position.[404]

Recommendations

It is recommended that C-KMC be incorporated as part of routine newborn care for premature and low birth-weight infants within the public and private health sector in South Africa. The infant should only be removed from the kangaroo position for diaper changes and bathing/cleaning (of the infant and the mother). The infant can be massaged using the technique described under section 11.5.1.5.3 during these times, but the infant should not be removed from the KP solely for the purpose of massaging. When removed from the KP for an extended period of time, the infant must be placed securely in one of the positions as described under section 11.5.1.5.3. When making use of C-KMC, the mother will sleep in a semi-reclined position with her baby secured in the kangaroo position. Fathers and selected family members can also assist by relieving the mother a few times a day. However, it is important to note that the thermoregulation of the infant that occurs during KMC is unique to the mother, and the baby might overheat when placed on the father's chest in rare instances.[405] This should be monitored whenever the baby is placed with someone other than his mother.

If it is not possible for the mother to perform C-KMC, all premature and low birth-weight infants must at least receive I-KMC, as many sessions as possible throughout the day, with each session lasting at least one hour. The infant must also be placed in the KP as part of pain management during procedures. The positions described under section 11.5.1.5.3 must be employed whenever the child is not in the KP, and the massage protocol described earlier can also be combined with the I-KMC care.

Each hospital needs to have a written policy and guidelines on practising KMC, and this information should be made available to parents. If a hospital is starting up a KMC unit, or planning on incorporating KMC at their hospital for the first time,

404 *Ibid*.
405 Ludington-Hoe SM *et al* (2008) 3-23.

it is important that they seek guidance from institutions that already successfully run KMC programs, especially in terms of weight at discharge and follow up programs.

11.5.1.5.6 Breastfeeding

First and foremost it is important to note that it is the mother's decision how her infant should be fed, be it formula or breastfeeding, and a decision should not be made without her input or consent. As health care professionals it is our duty to make sure that the mother makes an informed decision and that she is aware of all the benefits of breastfeeding. There are strict guidelines on promoting breastfeeding in South Africa (especially in the government sector) due to its nutritional, health and economic benefits.[406]

The current global recommendations state that infants should ideally be exclusively breastfed for the first six months of life. Thereafter, feeding must be supplemented with appropriate complementary foods while breastfeeding can continue up to the age of two years or beyond.[407]

Benefits of breastfeeding

According to the WHO/UNICEF, breastfeeding "is an unequalled way of providing ideal food for the healthy growth and development of infants; it is also an integral part of the reproductive process with important implications for the health of mothers." [408]

Breast milk is composed of various nutritional as well as non-nutritive components which are important for an infant's growth and development.[409] The macronutrients found in breast milk include protein, fat, and carbohydrates mostly derived from lactose. The micronutrients include a number of vitamins and minerals.

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406 Department of Health South Africa *Infant and Young Child Feeding Policy* (2013).

407 WHO/UNICEF *Global Strategy for Infant and Young Child Feeding* (2003).

408 WHO/UNICEF(2003) 7.

409 Ballard O and Morrow AL "Human milk composition: Nutrients and bioactive factors" (2012) *Pediatric Clinics of North America* 60(1):49-74; Riordan J "The biological specificity of breastmilk" in Riordan J and Wambach K (eds) *Breastfeeding and Human Lactation* (2010) 117-161.

Human breast milk also contains many non-nutritive, bioactive factors, which demonstrates that breast milk is not "merely nutritional", but also possesses "medicinal qualities that have a profound role in infant survival and health".[410] Included in these bioactive components are growth factors and immunological factors.

The composition of breast milk is also dynamic and the levels of certain components vary during feeds, between feeds, between individuals and also changes depending on the age of the infant. Preterm milk also differs greatly in composition to the milk produced by mothers who deliver at term in order to provide for the unique nutritional and health needs of these infants, further promoting the use of breast milk to feed preterm infants. Preterm milk "has higher levels of energy, lipids, protein, nitrogen, fatty acids, some vitamins, and minerals. In addition, preterm breast milk has higher levels of immune factors... than term breast milk".[411]

Breastfeeding also has psychological benefits for both the mother and the infant. It can encourage attachment between the mother and infant on a hormonal level through the release of oxytocin and prolactin.[412] Mothers of low-birth-weight babies have expressed that being able to provide milk to their babies gave them hope and pride in knowing that they were contributing to the health and well-being of their children[413] and lactation can even positively affect the mother's stress responses.[414] Evidence further suggests that breastfeeding has a positive long term effect on the cognitive outcomes of the very-low-birth-weight infant.[415]

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410 Ballard O and Morrow AL (2012) 5.

411 Riordan J "The biological specificity of breastmilk" in Riordan J and Wambach K (eds) (2010) 131.

412 Hahn-Holbrook J *et al* "Breastfeeding and maternal mental and physical health" in Spiers MV et al (eds) *Women's Health Psychology* (2013) 414-429; Wiessinger D *et al* The Womanly Art of Breastfeeding (2010).Author page numbers please.

413 Rossman B *et al* "'They've walked in my shoes': Mothers of very low birth weight infants and their experiences with breastfeeding peer consellors in the neonatal intensive care unit" (2011) *Journal of Human Lactation* 27(1):14-24.

414 Hahn-Holbrook J *et al* (2013) 414-429.

415 Tanaka K *et al* "Does breastfeeding in the neonatal period influence the cognitive fuction of very-low-birth-weight infants at 5 years of age?" (2009) *Brain and Development* 31:288-293.

Baby friendly hospital initiative

The World Health Organization and UNICEF launched the baby friendly hospital initiative (BFHI) in the early 1990's in response to the 1990 Innocenti Declaration which promotes practices that protect, promote and support breastfeeding.[416]

The minimum criteria for attaining BFHI hospital status is summarised as the "Ten steps to successful breastfeeding" and read as follows:

Every facility providing maternity services and care for newborn infants should:

1. Have a written breastfeeding policy that is routinely communicated to all health care staff.
2. Train all health care staff in skills necessary to implement this policy.
3. Inform all pregnant women about the benefits and management of breastfeeding.
4. Help mothers initiate breastfeeding within a half-hour of birth.
5. Show mothers how to breastfeed, and how to maintain lactation even if they should be separated from their infants.
6. Give newborn infants no food or drink other than breast milk unless *medically* indicated.
7. Practice rooming in – allow mothers and infants to remain together – 24 hours a day.
8. Encourage breastfeeding on demand.
9. Give no artificial teats or pacifiers (also called dummies or soothers) to breastfeeding infants.
10. Foster the establishment of breastfeeding support groups and refer mothers to them on discharge from the hospital or clinic.[417]

However, the issue was raised that these original guidelines were not necessarily sensitive to the specific needs of preterm, low-birth-weight and sick infants in NICU and their mothers A multidisciplinary team of breastfeeding experts were

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416 WHO/UNICEF *Global Strategy for Infant and Young Child Feeding* (2003).
417 WHO/UNICEF(2003) 3.

tasked with expanding the original guidelines to take the special needs of these vulnerable infants into account. As a result, some of the steps were revised, and three guiding principles for successful breastfeeding were added to the guidelines:

Guiding principles

1. The staff attitude toward the mother must focus on the individual mother and her situation.
2. The facility must provide family-centred care, supported by the environment.
3. The health care system must ensure continuity of care, that is, continuity of pre-, peri- and postnatal and post discharge care.

Expanded Ten Steps

1. Have a written breastfeeding policy that is routinely communicated to all health care staff.
2. Educate and train all staff in the specific knowledge and skills necessary to implement this policy.
3. Inform all hospitalized pregnant women at risk for preterm delivery or birth of a sick infant about the management of lactation and breastfeeding and benefits of breastfeeding.
4. Encourage early, continuous, and prolonged mother-infant skin-to-skin contact (kangaroo mother care) without unjustified restrictions. Place babies in skin-to-skin contact with their mothers immediately following birth for at least an hour. Encourage mothers to recognize when their babies are ready to breastfeed and offer help if needed.
5. Show mothers how to initiate and maintain lactation and establish early breastfeeding with infant stability as the only criterion.
6. Give newborn infants no food or drink other than breast milk unless *medically* indicated.
7. Enable mothers and infants to remain together 24 hours a day.
8. Encourage demand feeding, or when needed, semi-demand feeding as a transitional strategy for preterm and sick infants.
9. Use alternatives to bottle feeding at least until breastfeeding is well established and use pacifiers and nipple shields only for justifiable reasons.

10. Prepare parents for continued breastfeeding and ensure access to support services/groups after discharge.

Alternative feeding methods

As these vulnerable infants might not yet be ready for oral feeds, tire quickly during breastfeeding or still struggle with suck-swallow-breathe coordination, it is important to look at alternative feeding methods to direct breastfeeding.

The gestational age generally accepted as the norm for initiating direct breastfeeding is 34 weeks, but it is essential to consider each case individually.[418] If the infant is not yet ready for suckling at the breast, international guidelines suggest that alternatives to bottle feeding be used until such time as breastfeeding has been established. Cup feeding of expressed breast milk is most commonly used as an alternative or supplement to breastfeeding in these infants. Other means of oral feeding include spoon and syringe feeding. Infants being fed through a naso-gastric tube can also receive expressed breast milk.

Maintaining milk supply

Breast milk is produced based on demand, and if the breasts are not drained of about 67% regularly, total daily production will start to decrease.[419] Because of this it is essential that mothers of premature infants unable to breastfeed should regularly express breast milk to maintain their production levels. It is highly recommended that these mothers receive support and guidance from a lactation consultant or other suitably skilled health professional during this time.

Non-nutritive sucking (NNS)

As mentioned earlier in this chapter, non-nutritive sucking plays an important role in pain management of premature and low-birth-weight infants. It also has numerous other benefits, including improved glucose utilisation due to increased

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418 Riordan J "The biological specificity of breastmilk" in Riordan J and Wambach K (eds) (2010)Author please provide page numbers.

419 Smith LJ and Riordan J "Breastfeeding and human lactation" in Riordan J and Wambach K (eds) *Breastfeeding and Human Lactation* (2010) 253-290.

insulin secretion, improved self-regulation, and it can assist with the development of suck-breathe-swallow coordination.[420]

Seeing as it plays such an important role in development, the infant should be presented with the opportunities and the means to be able to perform this task. "The ideal way to provide non-nutritive sucking is to start on the mother's expressed breast".[421] Placing the infant at the recently pumped breast not only provides him with an NNS opportunity, but can also positively affect the mother's milk production. The emptied breast can also be used for NNS opportunities during gavage feeding, allowing the infant to taste the milk and for oral stimulation.[422]

According to the BFHI and the original "Ten steps to successful breastfeeding", the use of pacifiers is strongly discouraged. However, the expanded ten steps allow for the use of pacifiers in the NICU for justifiable reasons.

In her research van der Westhuyzen[423] argues that pacifier use within the NICU could be ethically justified due to the needs of the premature infant, as well as the nature of the NICU environment. She suggests the following ethical guidelines for pacifier use:

- Hospitals should have a policy on the usage of pacifiers for NNS in the NICU
- Pacifiers will only be available on prescription basis by the Pediatrician/Neonatologist and Speech Therapist.
- Pacifiers will only be prescribed to infants separated from their mothers. If a mother is able to offer her infant NNS opportunities on an expressed breast it should be preferred above the use of a pacifier.

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420 Lubbe W (2008) Author please provide page numbers.

421 Lubbe W (2008) 141.

422 Hurst NM and Meier PP "Breastfeeding the preterm infant" in Riordan J & Wambach K (eds) (2010) 425-470.

423 Van der Westhuyzen A *The Use of Pacifiers for Non-nutritive sucking in South African Neonatal Intensive Care Units: Ethical Considerations* (2015) author please provide page numbers.

- Pacifiers should be used for NNS while the infant receives painful interventions and during gavage feeding. During painful stimuli, a sweet substance like breast milk or sucrose can be offered with the pacifier.
- Once breastfeeding (on the breast) is being initiated, pacifier usage should be minimised or preferably [sic]. A pacifier should only be offered during painful stimuli or periods when the infant cannot be consoled.
- Prescribed pacifier should be appropriate for the infant's age and weight to limit orthodontic influences and still minimise the effect on breastfeeding.
- Pacifiers should be sterilised according to NICU protocol.
- Parents should sign an informed consent form when choosing to use a pacifier. They still have the autonomous right to decide to refuse pacifier usage.[424]

It is recommended that these guidelines set out by van der Westhuyzen be followed when using pacifiers for NNS, with the one exception of rather using breast milk than sucrose during painful stimuli because of reasons outlined earlier in this document. When a pacifier is prescribed, it is also very important that it is appropriate for that specific infant, and the healthcare professional prescribing the pacifier should be knowledgeable in this field.

Breastfeeding and HIV

South Africa adopted the 2010 WHO guidelines on HIV and infant feeding in 2013, which indicate that an HIV negative child born to an HIV positive mother should ideally be exclusively breastfed for the first six months of life, while the mother takes antiretroviral treatment as prescribed.[425] The infant should also receive antiretroviral prophylaxis for the first six weeks of life.[426] Appropriate complimentary feeds should be introduced after six months, and the mother should continue to breastfeed until the infant is one year of age (all the while continuing her ARV treatment). If the baby and mother are both HIV positive, the

424 Van der Westhuyzen (2015) 52-55.

425 Department of Health, South Africa *Infant and Young Child Feeding Policy* (2013); WHO/UNAIDS/UNFPA/UNICEF *Guidelines on HIV and Infant Feeding 2010: Principles and Recommendations for Infant Feeding in the Context of HIV and a Summary of Evidence* (2010).

426 Yezingane Network/UNICEF *Questions and answers: Infant feeding in the context of HIV in South Africa* (2011, original produced 2010).

infant can be breastfed according to regular recommendations mentioned earlier in this document.[427]

11.5.1.5.7 Family involvement

Family involvement is the last of the developmental support care measures to be discussed in this chapter. Family centered NICU care empowers parents to care for their premature, low-birth-weight or sick infants and offers the opportunity to humanise the hospital experience for all involved.[428] Some guidelines on promoting family involvement include educating parents on stress and stability cues of the infant,[429] giving as much care-taking responsibility to the parents as they are comfortable with, and providing opportunities and privacy for breastfeeding and KMC.[430]

11.6 JOINT ATTENTION INTERVENTIONS

Joint attention interventions applicable to the NICU environment mostly revolves around the recognition of the infant's cues and the parents' ability to sensitively respond to it, otherwise referred to as parental sensitive-responsiveness.[431] These interventions have been found to have positive effects on the cognitive outcomes of the child.[432]

Parental sensitive-responsiveness can be seen as the building blocks of high quality parent-child transactions, which if established early, can have long term positive effects on the parent-child relationship. More specifically, it can serve to minimise stress, permit the parents to have a more positive perception of their child and to increase their confidence in their abilities as parents.[433]

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427 WHO/UNAIDS/UNFPA/UNICEF (2010).

428 Aucott S *et al* "Neurodevelopmental care in the NICU" (2002) *Mental Retardation and Developmental Disabilities Research Reviews* 298-308; Nair MNG *et al* "NICU Environment: Can we be ignorant?" (2003) *Medical Journal Armed Forces India* 59:93-95.

429 See par 11.7 below for more details.

430 Nair MNG *et al* (2003) 93-95.

431 Guralnick MJ "Preventive interventions for preterm children: Effectiveness and developmental mechanisms" (2012) *Journal of Developmental and Behavioral Pediatrics* 33(4):352-364.

432 Clark GJ and Schlabach TL "Systematic review of occupational therapy interventions to improve cognitive development in children ages birth – 5 years" (2013) *The American Journal of Occupational Therapy* 67(4):425-430.

433 Guralnick MJ (2012) 352-364.

Sleep and awake states

Before discussing infant cues, it is important to understand the different sleep-wake states of the infant, as this has a great impact on when intervention and general interaction can and should ideally take place. The infant generally has six different states which include two sleeping and four awake states:[434]

- Sleep states
    - Quiet sleep – This is the state during which the infant grows. His eyes will be tightly shut, breathing will be regular and there will be no eye or facial movement. The infant will not wake easily from this state due to outside stimuli.
    - Active sleep – This state is linked with processing of information and learning. Rapid eye movements may be observed, as well as some body movements. Breathing might be irregular and sucking actions may be present.
- Awake states
    - Drowsiness – This is the state just before or just after sleep. The infant will open and close his eyes while in this state, but when the eyes are open he will look into the distance and not make eye contact. Breathing is faster and shallower than during sleep and the infant is not available for interaction.
    - Quiet awake/Calm alert – This is the ideal state for intervention and interaction as the infant is focused on the environment. There is minimal body movement and little or no facial expression, but the eyes are wide open and bright.
    - Active awake/Active alert – During this state the eyes are also mostly open, but not as bright as in the calm alert state. More generalised movement of the limbs can be observed, breathing is irregular and interaction is difficult. This might also be accompanied by grimacing and brief vocalisations. During this state the infant is very susceptible to sensory overstimulation.

[434] Faure M and Richardson A *Baby Sense* (2010); Foreman SW *et al* "Preterm infant state development: Individual and gender differences matter" (2008) *Journal of Obstetric Gynecologic & Neonatal Nursing* 37(6), 657-665; Lubbe W (2008) Author please provide page numbers.

- Crying – The infant will cry for at least 15 seconds, accompanied by vocalisation, skin colour changes and increased general motor activity. Premature babies in this state need consolation and assistance to return to a calmer state, as they do not yet have the skills required to self-regulate.

Younger preterm infants have a seventh state, termed the indeterminate state, undifferentiated sleep or transitional sleep,[435] the presence of which is indicative of immature neurological functioning.[436]

Infants generally move through the states in the order listed above, passing through quiet sleep to active sleep to drowsiness to quiet awake to active awake to crying. However, it is not uncommon for the preterm infant to skip states and to struggle with smooth transitions between them. Therefore it is important to know how to assist them in modulating their states.

Specific stimulation can either assist the infant to return to a previous state, or to continue on to the next state.[437] For example, an infant in the drowsy state can either be facilitated into the quiet awake state through alerting sensory input (such as light touch and bright colours) or back to the active sleep state through calming sensory input (such as swaddling, rocking and self-regulatory behaviours).[438]

Understanding the use of especially calming sensory input to assist the infant to regulate his/her states is a valuable skill, as this might be used to prevent the infant from becoming over stimulated and ultimately transitioning into the crying state.

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435 Lubbe W (2008); Foreman SW *et al* (2008) 547-665. Author please provide page numbers for Lubbe.

436 Foreman SW *et al* (2008) 547-665.

437 Lubbe W (2008); Faure M and Richardson A (2010) Author please provide page numbers for these books.

438 Faure M and Richardson A (2010) Page numbers please.

Direct behavioural observation is still the most reliable and efficient method of determining an infant's state,[439] and parents should be educated on recognising and responding appropriately to the different states.

Stress signals

The preterm infant can signal distress through the autonomic, motor and sleep-wake state systems, as well as through their interaction and attention.[440] It is important that health care professionals and parents understand these cues and react accordingly to avoid the infant becoming disorganised, stressed and inconsolable.

The table below categorises stress cues according to subsystem. The next section will discuss self-regulatory behaviour and how it can be encouraged in the infant.

Subsystem	Stress signal
Autonomic and physiological subsystem	Changes in heart rate
	Changes in respiratory rate
	Apnea
	Gasping
	Cyanosis
	Oxygen desaturation
	Skin colour changes
	Gagging
	Changes in thermoregulation
	Hiccupping, yawning and/or sneezing
Motor subsystem	Changes in muscle tone – hypotonicity or hypertonicity in the trunk and limbs

439 Foreman SW *et al* (2008) 657-665.

440 Guralnick MJ "Preventive interventions for preterm children: Effectiveness and developmental mechanisms" (2012) *Journal of Developmental and Behavioral Pediatrics* 33(4), 352-364; Lubbe W (2008) Page numbers?

	Finger or toe splaying
	Arching of the back
	Extension of limbs
	Fisting of hands
	Stop sign (hand held in front of face with fingers splayed)
	Jerky, repetitive movements
	Squirming
Sleep-wake subsystem	Inconsistent, poorly defined sleep states
	Abrupt state changes
	Limited time spent in deep sleep state
	Difficulty to stay awake
	Short periods of time in quiet-alert state
	Inconsolable crying
	Hyper alert
	Fatigue
Interaction and attention	Difficulty interacting
	Gaze aversion
	Easily over stimulated
	Inability to integrate more than one stimuli at a time
	Panicked facial expression

[Adapted from Lubbe and Guralnick][441]

Once the infant displays these signals, current stimulation must either be ceased, or calming stimulation can be used to return the infant to a previous sleep-wake

[441] Guralnick MJ "Preventive interventions for preterm children: Effectiveness and developmental mechanisms" (2012) *Journal of Developmental and Behavioral Pediatrics* 33(4):352-364; Lubbe W (2008) Page numbers?

state and to calm the nervous system. Note that only one input be given at a time, as even calming stimulation can over stimulate an already stressed baby (e.g. do not rock and talk to the baby at the same time).

Self-regulation

Self-regulatory behaviours are behaviours employed by the infant to regulate his own states without needing external input. However, preterm babies usually do not possess these skills, and as such they need assistance from caregivers and/or health care workers to learn how to utilise them. Self-calming strategies include non-nutritive sucking, foot bracing, thumb or fist sucking, face touching, bringing hands to midline, finger grasping and bringing hands to chin.[442] The infant can be assisted with these behaviours by positioning his body to facilitate these strategies (e.g. positioning with the hands close to the face) and modifying the environment appropriately.

11.7 POST DISCHARGE OCCUPATIONAL THERAPY INTERVENTION

Children born prematurely are at greater risk for neurodevelopmental disabilities, sensory impairments, cognitive, motor and behavioural problems.[443] As such, it is very important that these children receive adequate follow up and therapeutic intervention post discharge in order to alleviate these difficulties.

“The transition to home provides a more comfortable and familiar setting for families but also brings about an entirely new set of responsibilities”.[444] The parents are now solely responsible for the infant’s well-being, and they might experience alleviated stress and anxiety.

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442 Lubbe W (2008); Faure M and Richardson A (2010) Page numbers for these two books please.

443 Aucott S et al "Neurodevelopmental care in the NICU” (2002) *Mental Retardation and Developmental Disabilities Research Reviews* 8:298-308; Benzies KM *et al* “Key components of early intervention programs for preterm infants and their parents: A systematic review and meta-analysis” (2013) *BMC Pregnancy and Childbirth* 13(Suppl 1), S10; Clark GJ and Schlabach TL “Systematic review of occupational therapy interventions to improve cognitive development in children ages birth – 5 years” (2013) *The American Journal of Occupational Therapy* 67(4):425-430.

444 Guralnick MJ (2012) 7. Author please check page reference.

In his review of preventive interventions for preterm children, Guralnick[445] recommends that preventive intervention programmes should be implemented across the entire early childhood period and suggests that the Developmental Systems Approach (DSA) be used. This approach was specifically designed to address the development and implementation of early childhood intervention programs for children with already established disabilities, as well as for children at risk for developmental delays and disabilities. In line with the DSA, intervention programmes should address all three of the following components:

- Individual child development
- Family patterns of interaction
- Family resources

Furthermore, Benzies *et al*[446] identified three main categories of intervention strategies that may affect the outcomes of the preterm infant, namely psychosocial support for the parents, parenting education, and therapeutic developmental support of the child.

The rest of this section will be devoted to the discussion of the components identified by Guralnick, as well as how the intervention strategies identified by Benzies *et al* might be employed by the Occupational Therapist to address these components.

Individual child development

Every infant has child-specific risks, which interact with protective factors – ultimately affecting the child's development.[447] By carefully assessing the infant's individual strengths and challenges, the Occupational Therapist can implement an intervention plan specific to the infant, supporting his developmental needs.

Developmental support of the child has been discussed at length in this chapter as it pertains to the NICU environment. However, it is important that this support continues post-discharge. Other than direct therapeutic developmental

445 Guralnick MJ (2012) 7. Author please check page reference.
446 Benzies KM *et al* (2013) S10.
447 Guralnick MJ (2012) ?. Author please check page reference.

intervention supplied by the therapist, the child's development can further be supported by educating the parents on infant growth and development.[448]

Family patterns of interaction

There are three types of family patterns of interaction, namely parent-child transactions, family orchestrated child experiences and health and safety provided by the family. Of these three, parent-child transactions play the most important role during the first three years of life and are also seen as core features of the DSA.[449]

As discussed above, parental sensitive-responsiveness plays a large role in the development of positive parent-child transactions. The development of parental sensitive-responsiveness within the NICU was discussed earlier, but once again it is important to ensure carry-over into the home for positive long term results.

To address family patterns of interaction, the therapist can make use of both the psychosocial support and parental education intervention strategies. Ideally the parents would have received some education on distress signals and self-regulation while their infant was still in NICU. If this is the case, the Occupational Therapist can emphasise the importance of responding appropriately to these signals, and make further suggestions within the home to accommodate the infant and his needs. It the family did not receive any education on this prior to discharge, the therapist would spend more time on establishing parental sensitive-responsiveness, ensuring a solid foundation for future parent-child transactions.

Family resources

Family resources can be subdivided into the personal characteristics of the parent, and material resources.[450] Once again, both psychosocial support and parental education can serve to address the underlying components of the personal characteristics of the parent, namely:

- Mental and physical health

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448 Benzies KM *et al* (2013) S10.
449 Guralnick MJ (2012) ?. Author please check page reference.
450 *Ibid*.

- Intellectual ability
- Attitudes and cognitive readiness
- Coping style
- Perceived confidence and competence.[451]

Higher levels of maternal distress during the first year of a child's life has been associated with lower levels of sensitive-responsiveness,[452] which indicates that family resources directly affect family patterns of interaction, which in turn affect individual child development. It is thus imperative that these components be addressed as part of the intervention program.

Material resources, namely financial resources and social support, can be addressed by assisting the family with realistic future planning. The therapist could give insight into what equipment the child might need to use over the next few years (including mobility devices, communication devices etc.), as well as put the family in touch with providers and manufacturers of such devices. They could also plan for future schooling and therapy. In this way, the family has the chance to financially plan for the future. The therapist can also connect the family to support groups and relevant professional organisations for ongoing social and educational support.

Location of service delivery

Home visits are described by Weiss[453] as a "necessary but not sufficient, component" of intervention programmes aimed at families with young children. Home visits are well documented as forming part of a number of early intervention programmes, especially in the developed world.

Providing intervention in the family's home can prove beneficial for a number of reasons. If the infant is newly discharged, the family might not want to leave the house with the child due to health and safety fears. The infant might also be more comfortable in his home environment and home visits can be scheduled around

451 Guralnick MJ (2012) 21.
452 *Ibid*.
453 Weiss HB "Home visits: Necessary but not sufficient" (1993) *The Future of Children* 3(3), 113-128.

the family's (and the child's) routine. During home visits the therapist is able to suggest practical adaptations to the environment and obtains a more holistic view of the child and his development.

Many families also have other small children in the home which might make it difficult to leave the house, or the parents might find it difficult to attend therapy due to heavy work schedules.[454] Being willing to accommodate the family in this way may have a positive effect on the relationship between the therapist and the parents.

However, home visits might not always be a feasible option in South Africa, especially in the government sector where therapist shortages might make the time demands of home visits impractical. Furthermore, some families might see home visits as intrusive and might not welcome the idea of a therapist in their homes.[455]

Even though there are many benefits to performing home visits, one has to evaluate each case individually and decide what the best course of action would be for that family. Furthermore, Shonkoff *et al*[456] reported no differences in outcome between centre-based and home-based interventions, further supporting the premise that the location (as all other aspects) of early intervention services should be tailored to the family's needs.

11.8 CONCLUSION

As the high risk infant presents with such a multitude of healthcare needs, it is important that a multi-disciplinary team be available to assist and support the family during their time in NICU, as well as post-discharge. The Occupational Therapist forms an integral part of this team, and with their unique skill set can prove to be a great asset in the NICU environment and beyond.

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454 *Ibid*.

455 *Ibid*.

456 (1992) as cited in Farren DC "Another decade of intervention for children who are low income or disabled: What dowe know now?" in Shonkoff JP and Meisels (eds) *Handbook of Early Childhood Intervention* (2000) 510-548.

Ideally the Occupational Therapist would be available on a full time basis within the NICU to provide neurodevelopmental care, as well as any other services the infants and their families might require. If this is not possible, it is of paramount importance that the infant be referred early (within the first few days of life), to maximise the impact of intervention. Occupational Therapy services can further be extended through training of other staff members and parents in the NICU on topics such as positioning, handling and environmental adaptation.

Medical stabilisation and care can no longer be the only role of the NICU. Those first few weeks of extra-uterine life is the foundation on which further development will be built, and as healthcare providers we need to embrace this as part of our caregiving model by expanding our teams and allowing space for the expertise of different team members.

CHAPTER 12

(Lyn Preston)

CRITICAL CARE GUIDELINES: A PSYCHOLOGICAL PERSPECTIVE

12.1 INTRODUCTION

Studies have shown that psychological distress is common among parents of hospitalized premature neonatal infants. One can even go as far as to say that parents of hospitalized premature infants are at risk for developing psychological symptoms which could be detrimental to both parents and infant.

Bernard, Williams, Storfer-Isser[457] site previous studies of Meyer *et al*[458] and Miles[459] as having reported psychological distress among parents whose infant were hospitalized in the NICU. Typical post traumatic stress reactions such as irrational reasoning and thinking, guilt, helplessness, anxiety, and depression have been noted in most of the studies. The premature birth of a child can be seen as a traumatic event for parents and family.

Jotzo and Poets,[460] Kaaresen, Ronning, Ulvund and Dahl[461] strongly advocate preventative interventions. They suggest that these interventions could potentially improve the experience of the NICU parent which would have future benefits for the child and the parents. Brief cognitive–behavioural (CBT) interventions are

457 Bernard RS *et al* "Brief cognitive–behavioral intervention for maternal depression and trauma in the neonatal intensive care unit: a pilot study" (2011) *Journal of Traumatic Stress* 24(2):230–234.

458 Meyer EC *et al* "Psychological distress in mothers of preterm infants" (1995) *Journal of Developmental & Behavioral Pediatrics* 16(6):412–417.

459 Miles MS "Parents of critically ill premature infants: sources of stress" (1989) *Critical Care Nursing Quarterly 12*:69–74.

460 Jotzo M and Poets CF "Helping parents cope with the trauma of premature birth: an evaluation of a trauma-preventive psychological intervention" (2005) *Pediatrics* 115:915–919.

461 Kaaresen PL *et al* "A randomized, controlled trial of the effectiveness of an early intervention program in reducing parenting stress after preterm birth" (2006) *Pediatrics* 118(1):e9-e19.

widely used in reducing traumatic symptoms in post traumatic stress cases. Cobiella, Mabe and Forehand[462] found that CBT techniques were effective in decreasing distress and anxiety in NICU mothers.

It is with this in mind that it is suggested that clearer guidance and support for both parents and professionals are needed. Specifically from a psychological point of view, counselling interventions and support can facilitate and ease many of the required medical procedures that are vital to the neonate.

Psychological support empowers the parents by promoting communication and a greater understanding between all role players. Psychological interventions are aimed at various individuals and are given on various levels. Firstly, support to the medical practitioner by providing additional psychological information regarding the patient (where applicable), parents and significant others within the presenting situation and secondly psychological support is also directly provided to all those involved in the NICU situation. This is done by individually strengthening coping skills, promoting communication and understanding and providing appropriate information for all role players during the period in the NICU. Knowledge eases fears and brings understanding and insight making it easier for a person's coping skills to take effect and enhancing resilience in the human soul.

By bringing everyone on board, all parties are empowered regarding knowledge, information and situational understanding which would positively promote actions and decisions which have to be taken in the best interest of the neonate.

462 Cobiella CW *et al* "A comparison of two stress-reduction treatments for mothers of neonates hospitalized in a neonatal intensive care unit" (1990) *Child Health Care 19:*93–100.

12.2 ETHICAL ISSUES REGARDING DECISION MAKING AND PSYCHOLOGICAL SUPPORT

It is not the psychologist's role to make any life or death decisions regarding the newborn, but rather to support the family during the occurrences that develop within the situation. It is therefore highlighted that psychological input revolves around quality of life and not sanctity of life. In order to achieve this standard one must consider the best interests of the child principle.

We recognise that there are very real difficulties in knowing what is best for a baby. Nevertheless we concluded that the principle of best interests should remain a central one in decision making about new born babies and children.[463]

In a South African context the central consideration when making any decision regarding the child, is the best interests of the child.[464]

With this concept defined, the next important factor to consider is the interests and rights of the parents and other significant parties who are involved with the neonate.[465]

The psychological input and support must consequently holistically encompass all individuals who have a vested interest in the neonate and globally support the individual within the presenting situation while also empowering specific role players as the need arises in order to facilitate difficult decision making and ethically work in the best interests of the neonate.

To conclude, psychological input must be ethically considered, situationally appropriate and tailored to support all individuals involved in the NICU situation

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463 NCOB (2006) 15-17, 159-162.

464 See par 2.4.5 above for a detailed description of the best interests of the child standard.

465 For a definition of "family member" see section 1 of the Children's Act 38 of 2005.

12.3 PSYCHOLOGICAL SUPPORT OF THE VARIOUS ROLE PLAYERS WITHIN PRESENTING SITUATION AND WITH THE DECISION-MAKING PROCESS

12.3.1 Parents and primary caregivers

In general, parents have a legal and moral authority to make decisions in their child's best interests in all spheres of the child's life. In order to fulfil this moral and legal responsibility a parent needs appropriate information and support, especially if it concerns critical care decisions. During this time there is often life threatening situations and exceptional uncertainty and fluctuations regarding the neonate's condition, the prognosis and very often overall circumstances that continually change. As the parents involved in the crisis are more than often first time parents, critical care decisions regarding neonates can be especially traumatic. There is also often difficulty regarding communication between doctors and parents as the situation is so precarious and unpredictable. Furthermore, parents can either become over controlling and overbearing, resulting in unrealistic decisions or demands or contrary, totally withdrawn and distant, making no decisions and leaving everything to the medical personnel.

To provide optimal psychological support for parents and medical personnel alike, a network of support is needed which involves partnerships of honesty, understanding and care. Appropriate and relevant medical information must unreservedly flow from the medical practitioner to the parents and parental responses must likewise be communicated back to the doctor.

Significant others (grandparents, religious leaders, siblings etc) should all be considered and incorporated in the decision making process if requested by the parent or primary caregiver. Reciprocal information should be given to the appropriate health care professionals in order that they can also align themselves to the needs of the parents, patients and the situation.

12.3.2 Nature of psychological support that should be given to parents and primary caregivers

The birth is the beginning; it is the start of two new phases of life. Regarding the child, it is the beginning of life and for the adult (parents) the beginning of parenthood. During this occurrence there are two ways the event can be experienced.

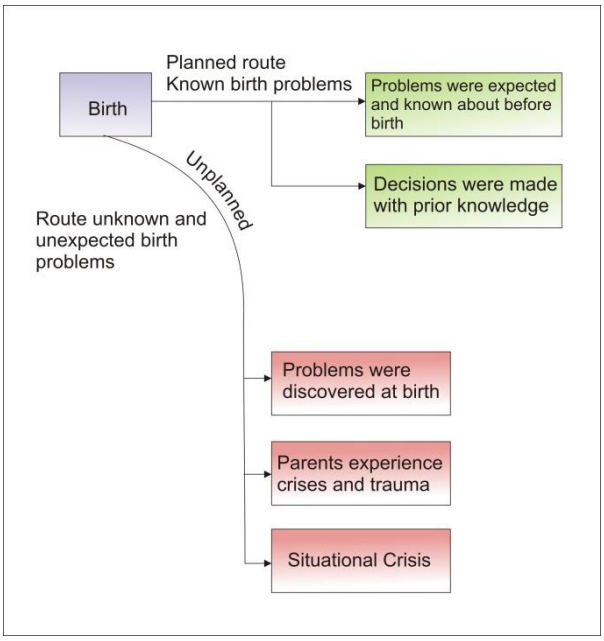


Figure 1. The birth experience

- First situation that is considered is the one where known or expected problems regarding the birth are identified prior to the birth. Regarding this situation the mother, or parents, acknowledge there is a problem with the child and they consciously choose to continue with the pregnancy. Among other complications, physiological problems leading to expected premature delivery, expected abnormalities (eg, Downs Syndrome being diagnosed during pregnancy) or difficulties regarding problematic or high risk pregnancies can be considered.

Regarding this scenario psychological support should be part of the entire pregnancy, preparing all those involved for the event and the projected

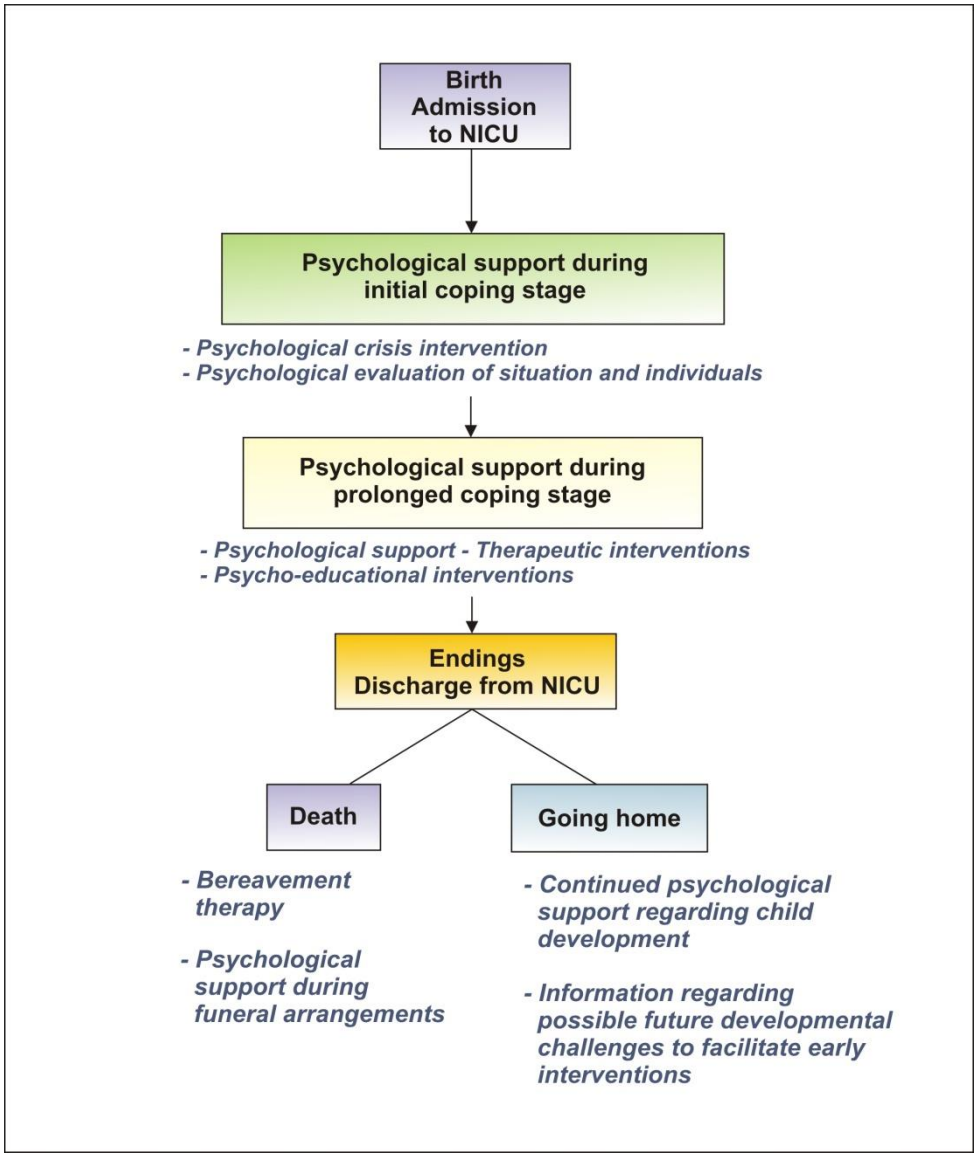
consequences. Psychological interventions with the parents, primary caregivers and significant others regarding the birth must be facilitated before the birthing event. The pregnant woman and her family, who have chosen to continue with the pregnancy knowing that the child will have problems, are bound by a lifelong obligation with regard to caring and supporting the child. A team approach is therefore essential in order to promote communication and exchange of information and facilitate lifelong support for the parents and the child.

- Second situation refers to unknown or unexpected problems regarding the birth which are only discovered at birth. This is a more acute and intense situation where psychological intervention is introduced during the presenting situation or as soon as possible thereafter. Situation entailing sudden problems occurring with the mother or the infant, birth complications, birth after a traumatic event or encountering of a genetic defect at the birth or the death of the child all encompass situational crisis and traumatic circumstances which were unplanned or not foreseen.

Regarding this scenario psychological support should be available as needed as soon as possible after the birth as the new family is plunged into a seriously traumatic situation with no way out except to cope and push through. All parties involved with the birth should be engaged and crisis interventions must be used to effectively contain the situation. This initial intervention is usually a crisis intervention and not a typical therapeutic session. Psychological help during this period is secondary service as the family are usually intensely involved with the medical staff and their own personal reactions. However a psychologist will need to know details and understand the background regarding the situation in order to plan the therapeutic route forward, therefore once the situation has been medically stabilised continued psychological support is essential.

12.3.3 Framework of psychological support given to parents and primary caregivers during the NICU admission and stay

Psychological neonatal support can be divided into stages which run in a circular pattern according to the presenting situation, the prognosis and progress of the neonate.



Stage 1: Initial coping stage

During this stage the initial impact of the traumatic situation has passed and the reality of the circumstances are becoming clear. As the infant is now admitted into the NICU the family is starting to come to terms with the hospital routines. Many of the hospital and NICU procedures and schedules are being assimilated in the family's personal routine. However, occurrences are still new and emotionally the family is still hopeful and positively directed, as they are still in the emotional euphoria of being new parents and having a child. The family and individual adjustment capabilities and coping skills are not really tested as the time is too short to evaluate how each individual will cope given future projected unpredictable prognosis and time frames.

Psychological support during the initial coping stage includes the following:

- Building up solid relationships with all parties involved.
- Familiarise the family with the hospital routines.
- Provide crisis trauma intervention when necessary depending on the outcomes of the neonate.
- Obtain necessary psychological information concerning family.
- Provide individual and group psychological interventions.
- Provide psycho educational support regarding applicable and requested information.

Psychological evaluations during the initial coping stage include the following:

- Personal relationship evaluations must be done of the entire family unit involved with the presenting situation as well as an assessment of the external support the family has.
- Environmental or situational evaluation which includes the length of stay of the neonate, the amount of negative stress provoking events (medical setbacks), possible long term effect on family routine, other stressful events present within the situation, eg, financial, job restraints etc.

Psychologists' role during the initial coping stage includes the following:

- Be available for in and out of hospital visits.

- Trying to see parents together as well as providing individual support.
- Facilitate team approach to ensure optimal communication.
- Be a vital link between the medical personnel and the family.
- Have enough information for networking with other support systems.
- Being realistic and conveying an honest, accurate message to and from client.
- Monitor family with regard to psychological adjustment and coping skills.
- Identify possible problems and be proactive in providing alternatives.
- Make follow up supportive sessions with the family – keep in contact especially during long hospital admissions.
- Psycho educational inputs: Give general facts concerning premature births and tendencies associated with a 22 week gestation, 23-25 week gestation and a > 26week gestation period.

Stage 2: Prolonged coping stage

During this stage the general hospital routines are known to the family of the neonate. The situation regarding the infant has become clearer and if serious, more medical facts are evident. The family realises that the situation will require prolonged absence from family and daily routines, which will impact on each individual. Prolonged and drawn out trauma is now evident as the family has to stretch their coping skills by adjusting to the new situation. The situation presents the family with endless uncertainty and unforeseen problems as the neonate either thrives or deteriorates. Anxiety and depression become problematic within the situation and many of the adults are affected. If the situation becomes critical hopelessness and helplessness often set in, compounding situational anxiety and depressive tendencies which the parents are most probably already experiencing. The mother too can be especially affected as post-partum depression is a very real threat.

Psychological support during the prolonged coping stage include the following:

- Sustaining positive relationships with all parties involved.
- Continued group and individual support.

- Continued promotion of communication between all parties involved, sustaining positive relationships between the medical personnel and the family.
- Creating new and sustaining previously acquired networks and linking support systems.

Psychological evaluations during the prolonged coping stage includes the following:

- Continual individual and group evaluations must be done of the entire family unit involved and monitoring of individual members is essential to ascertain levels of coping and functioning in order to timeously intervene with appropriate psychological support or referral for medication.
- Continual situational evaluations must be done regarding the presenting situation in order to prepare the family in the event of problems regarding the neonate.
- Re-evaluation of environmental or situational circumstances. This includes medical, financial, social factors that could impact on the situation and the family.

Psychologist's role during the prolonged coping stage includes the following:

- Mediate between family members and health profession workers if situation gets difficult.
- Provide a constant, regularly available support for individual and family members.
- Continually be realistic and convey messages honestly and accurately to parents and significant others as well as engendering realistic hope.
- Providing future projected psycho educational information.

12.3.4 Psycho-educational information provided to all parties during the coping stage in order to assist with decision making

12.3.4.1 Initial interventions

When an infant is admitted to the NICU parents commonly experience trauma as these new parents often have to face many harsh and invasive medical procedures that are required for the neonate. The NICU environment is also a medical environment where machines and unfamiliar equipment surround the new family. Parents think they have lost control because of an unfamiliar environment and the greatest source of stress often cited by these parents is loss of their expected and desired parental role.[466] They also report feeling so disappointed and frustrated that they cannot perform the normal parenting tasks (e.g., feeding) as they had expected and also a feeling of extreme distress and helplessness about not being able to protect their new born.[467] With the parents struggling to cope and with the uncertainty of the situation optimal support for the neonate is sometimes sadly lacking. This situation is compounded as many infants born preterm do not receive developmental services in the first months after hospital discharge.[468] Bearing this in mind, when one considers the South African context, neonatal support is sparser and even non-existent in certain areas.

It is with this in mind, that it is suggested that appropriate information be made available to the new parents which provides necessary facts. Medical aspects as well as psycho educational aspects must be covered that inform parents of the facts surrounding the immediate situation and also of future directed or projected difficulties and challenges that can be expected. Therefore the parents must be aware of any continued community support available, forming a link to a continuum of care, which is essential for the developing neonate. Continued

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466 Turan T *et al* "Effect of nursing interventions on stressors of parents of premature infants in neonatal intensive care unit" (2008) *Journal of Clinical Nursing* 17(21):2856–2866.

467 *Ibid*.

468 Dusing SC *et al* "Instituting parent education practices in the neonatal intensive care unit: an administrative case report of practice evaluation and statewide action" (2012) *Physical Therapy* 92(7):967-975.

psychological support must be available to the family during this entire process especially when the family has left the hospital.

Developmental facts which are vital for parents to know must be given to all parents, primary caregivers and significant others. Even though these facts may also be given by other members of the support team, bearing in mind the situation, repetition of important facts is essential. Considering the situation may seem overwhelming for new parents, psychological support is necessary to facilitate parental functioning and enhance coping skills, build resilience and reduce the effects of trauma.

Premature infants tend to have more intellectual difficulties as they grow up more slowly than previously suspected. Infants born preterm are at high risk of developmental disabilities and they will therefore benefit from early developmental intervention programs,[469] therefore it is beneficial for parental education regarding neonate support from the very start and ensuring this continues well into the child's school career.

Many people have different perceptions of a disability, what some individuals may see as a challenge others may see and a total disability. The parents involved in the presenting circumstances must be aware of all the facts surrounding their unique situation, in order to make realistic decisions in the best interests of their child, therefore psychological support, assistance and education, in the form of individual and family interventions, must be realistic, non-directive and dynamic. The family must begin to familiarise themselves with the reality of the presenting situation and psychologically begin to adjust.

469 *Ibid*.

There are four outcomes for the premature infant.

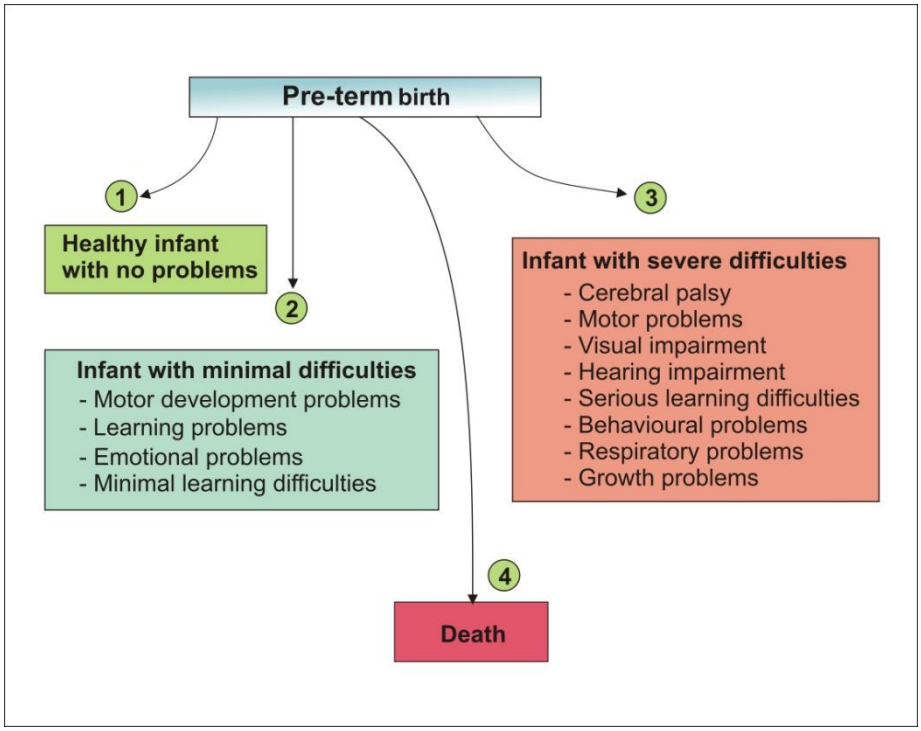

Figure 3.Outcomes for the premature infant.

The first outcome will be that the infant is healthy with no problems. This scenario is obviously the one hoped for, however as statistics indicate, a very low percentage of neonates are without problems and challenges.

The second outcome regarding the premature infant can be seen in the category of minimal problems and difficulties. This category usually reflects initial major medical concerns and challenges with recovery and eventual discharge; therefore survivors in this category may have more health problems and achieve less academically or have minimal challenges regarding future life developments. Within this group of neonates the problems tend to occur during physical development where the child presents as clumsy or has lower motor co-ordination; learning disabilities could also be evident later on in life. Parents must be educated to understand the impact that premature birth has on childhood development, to be able to screen early for any developmental delays or learning problems regarding their child. The nature of the disabilities must be delineated, that parents are aware of future challenges and that interventions can be made as

a course of preventative action. As the child develops learning emotional, behavioural and physical (motor development) challenges may also occur, again a parent who is aware of this can take appropriate action. Doctors and parents alike must be made aware and understand the impact that treatment after birth can have on the developing child with these moderate disabilities.

The third category is neonates with severe disabilities; these are seen as overt physical, intellectual and behaviour problems. Regarding the nature of these disabilities, one must realistically support parents and highlight the reality of the situation reminding them that their decisions are life time commitments. Psychological support must not be prescriptive or unintentionally directive, it must holistically sustain and maintain all the child's external support systems. However, realistic future actuality must be focussed on when counselling parents. Doctors too must assist parents to achieve a deeper understanding of the future needs of the child. Parents will never be able to completely project the difficulties they will face when supporting a disabled child until they have actually experienced the situation in detail, especially during the child's lifespan, where the child presents with different needs during different developmental phases. The psychologist can only assist by walking the path with the parents and supporting when necessary.

Psychological support during this scenario must realistically support the parents and empower them with coping skills, connect them to organisations and networks which can give lifelong support to the child as the child grows. Psycho education can also entail disability legislation and make parents aware of the rights of their disabled child.

The fourth outcome is one of finality as the neonate can die. This will be further discussed stage 3.

Stage 3: Endings

The final stage of the NICU admission and residency process, can be divided into two scenarios. Firstly, going home stage where the neonate is able to go home and proceed with family life as a family member and secondly the other ending

can be when the neonate passes away and the family are plunged into bereavement and loss.

Going home

During this time there are mixed emotions that the parents' experience, joy of eventually being parents and fear of being alone with the child and having to cope without professional support. Psychological support during this period revolves around final screening for post natal depression regarding the mother, assisting with confidence building and new family routines and reminding family about follow up protocols. Contact details of support groups and networks obtained during the hospital stay as well as the psychologist contact details are given to the new parents.

Psycho educational information to prepare mothers for the path forward includes giving an indication of the developmental milestones of a child, normalising the unique development of the child and promoting understanding and insight regarding the future situations. Promotion of constant monitoring of the child's development and referral to support therapist if necessary is important. Promote family involvement, cohesion and values and empower all family members, fathers, grandparents, significant others etc.

Loss/bereavement

Regarding this scenario the psychological support would include immediate assistance with the situation regarding crisis intervention and containment. Support with the unloading of emotions, guilt feeling and irrational thought processes. Support and assist on how to break news to siblings or other family members. Psychological assistance regarding funeral arrangements – giving options eg, undertakers or legal protocols (do not make the arrangements). Making sure the family is supported after the crisis and giving family members follow up procedures and information, (contact detail of support groups and alternative psychologists' numbers etc.) Contact minister or cultural leaders if required by the family.

12.3.5 Healthcare professionals

All healthcare professionals caring for the neonate have various responsibilities towards the parents or primary caregivers, the newborn, the hospital where the child has been born and towards themselves and their ethical codes of conduct. To promote best interests of the child principle healthcare professionals are often faced with ethical, financial, social and religious dilemmas. It is therefore advocated that all role players are actively involved and a team approach is undertaken to support the situation, the parents and themselves.

12.3.6 Healthcare administrators within the hospital context

In the private hospital sector administrative aspects are usually overseen by a case manager within each hospital environment. Their actions and decisions are usually prescribed and dictated by the various medical aids that the patient is a member of. Scale of benefits, limitations and various other restrictions are all individually specified and impact on the services that can be rendered by the hospital. In state driven hospitals there are no stringent guidelines and the final decisions usually lie with the medical practitioner in attendance. Psychological services although essential are seen as a support service and therefore take second place.

12.3.7 Conclusions and recommendations

Given the presenting situation a code of practice for psychological support should be part of professional guidelines to support all role players involved in NICU situations. Psychological support would facilitate interpersonal relations with all role players involved with the neonate and provide individual specialised support for the parents or primary caregivers of the child during difficult decisions which may have to be made.

ABBREVIATIONS

AAP	American Academy of Pediatrics
ABR	Auditory brainstem responses
ACRWC	African Charter on the Rights and Welfare of the Child
ADHD	Attention deficit hyperactivity disorder
ARV	Antiretroviral
BFHI	Baby friendly hospital initiative
BMJ	British Medical Journal
CA	Court of Appeal (UK)
CBT	Cognitive behavioural therapy
CC	Constitutional Court (RSA)
C-KMC	Continuous Kangaroo mother care
CMV	Cytomegalovirus
CPAP	Continuous positive airway pressure
CRC	United Nations Convention on the Rights of the Child
CRP	C-reactive protein
DSA	Developmental Systems Approach
ECMO	Extracorporeal membrane oxygenation
EHDI	Early hearing detection and intervention
EPICure	Studies done by the UK Institution for Women's Health
EWCA	England and Wales Court of Appeal
GG	Government gazette
GIT	Gastro-intestinal tract
HIV	Human immunodeficiency virus
HPCSA	Health Professions Council of South Africa
ICESC	International Covenant on Economic, Social and Cultural Rights
I-KMC	Intermittent Kangaroo mother care
ISMP	Institute for Safe Medication Practices
IVH	Intraventricular haemorrage
JCIH	Joint Committee on Infant Hearing
KMC	Kangaroo mother care

KP	Kangaroo position
MCT	Medium chain trigliserides
MDG's	Millennium Developmental Goals
NCOB	Nuffield Council on Bioethics
NEC	Necrotizing enterocolitis
NG	nasogastric
NICU	Neonatal intensive care unit
NIDCAP	Neonatal Individualized Developmental Care and Assessment Program
NJ	nasojejunal
NMR	Neonatal mortality rates
NNS	Non-nutritive sucking
NPUAP	National Pressure Ulcer Advisory Panel (USA)
NSRAS	Neonatal Skin Risk Assessment Tool
OAE's	Otoacoustic emissions
OG	oral gastric
PDA	Patent ductus arteriosus
PER	Potchefstroomse Elektroniese Regstydskrif
PICU	Paediatric intensive care unit
PN	parenteral nutrition
RCPCH	Royal College of Paediatrics and Child Health
ROP	Retinopathy of prematurity
RSV	Respiratory syncytial virus
SA	SA Law Reports
SAJHR	South African Journal on Human Rights
THRHR	Tydskrif vir die Hedendaagse Romeins-Hollandse Reg
TSAR	Tydskrif vir die Suid-Afrikaanse Reg
UK	United Kingdom
UNHS	Universal newborn hearing screening
UNICEF	United Nations International Children's Fund
USP	United States Pharmacopeia
WHO	World Health Organization
W	Witwatersrand Division

WLR	Weekly Law Reports (UK)

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