

The development of a neonatal communication intervention tool

by
Esedra Strasheim

Submitted in the fulfilment of the requirements for the degree

M.Communication Pathology
(Speech-Language Pathology)

in the
Department of Communication Pathology
Faculty of Humanities
University of Pretoria

Supervisor: Prof B. Louw
Co-supervisor: Prof A. Kritzinger

November 2009

Acknowledgements

My sincere thanks to

My dear Lord Jesus, who has given me the ability to work for Him. Thank you God for showing me the way every day.

Prof Brenda Louw and Prof Alta Kritzinger, thank you for guiding me in every step of this project. Thank you for encouraging me, teaching me and inspiring me to be passionate about ECI. Thank you for your guidance, reassurance and kind words.

Speech-language therapists and audiologists everywhere – without you this study would not have been possible.

Loina Bodenstein at the Department of Statistics for your words of wisdom as well as statistical analysis.

Dr Mike van der Linde and Mrs Rina Owen at the Department of statistics for the statistical analysis of the data.

Annelie Steenkamp in Kimberley who assisted me with completion of the study in the Northern Cape. Dankie vir jou waardevolle bydrae.

Erika Bostock and the therapists at Witbank hospital for the pilot study.

My colleagues and friends at the Baby Therapy Centre, for teaching me and inspiring me. Martie, dankie vir jou ondersteunende woorde. Liz, dankie vir jou entoesiasme en geduld. Gayle en Lizl, dankie dat julle my onder julle vierk geneem het. Tami en Elriza, julle weet nie wat julle daagliks vir my beteken nie. Dankie vir julle belangstelling en omgee (en proeflees)!

Elmien, for always asking about my progress. Dankie vir jou belangstelling!

Annette, for understanding how much this project meant. Dankie vir jou belangstelling, moed-inpraat, berading en gratis advies.

Sanet, for your constant interest. Dankie dat jy 'n spesiale vriendin is.

Delia, for 'holding my hand' at a crucial time this year. Ek waardeer jou baie.

Soné, for unconditional love and support throughout this project and everything that came with it. Dankie vir jou liefde – jy is waarlik 'n inspirasie.

Michelle, for kindness and support throughout my study. Ek het al oneindig baie by jou geleer en waardeer jou teenwoordigheid in my lewe.

Ma en Pa, for always being my home and my support-team. Dankie vir julle entoesiasme en aanmoediging met my studie. Dankie vir julle ore wat altyd luister en julle arms wat altyd oop is vir my - julle warmte en omgee dra my elke dag. Dankie vir julle onskatbare bydrae tot hierdie projek.

Eben, my brother, for being my friend as well as my sib and for continuous encouragement and support. Dankie dat jy altyd perspektief bring wanneer dinge deurmekaar begin lyk.

Abstract

Title: The development of a neonatal communication intervention tool

Researcher: Esedra Strasheim

Supervisors: Prof. B. Louw & Prof. A. Kritzinger

Department: Department of Communication Pathology

Degree: M.Communication Pathology

Comprehensive management in the neonatal nursery involves medical treatment of the infant, as well as developmental care and the provision of guidance, counselling and information to the family who are part of the decision-making process regarding the infant's care. Neonatal communication intervention is of utmost importance in a country such as South Africa, which has an increased prevalence of infants at risk for disabilities and where the majority of these infants live in poverty.

Speech-language therapists fulfil an important role in the neonatal nursery and are an integral part of the team involved with the high risk neonatal population. Local literature showed a dearth of information on the current service delivery and roles of speech-language therapists and audiologists in neonatal nurseries in the South African context. From an asset-based perspective it appears that the South African population receiving services in neonatal nurseries have unique characteristics. This provides speech-language therapists with ample opportunity to intervene, providing that intervention is well-timed in the neonatal nursery context.

The country-wide initiative to implement the evidence-based technique of kangaroo mother care indicates that speech-language therapists should recognise its importance and develop communication based materials and tools to complement this successful neonatal intervention. The aim of the research was to establish whether speech-language therapists have needs for assessment and intervention tools/materials in this context. The study

furthermore aimed to compile a locally relevant neonatal communication intervention instrument/tool for use by speech-language therapists in the neonatal nurseries of public hospitals in South Africa in order to propose a solution to address the shortage of tools in the public health context.

The study entailed descriptive, exploratory research. During Phase 1, a survey was received back from 39 speech-language therapists and two audiologists in six provinces. The data revealed that participants performed different roles in neonatal nurseries, which were determined by the environment, tools, materials and instrumentation available to them. Many participants were inexperienced, but were resourceful in their attempts to develop and adapt tools/materials. Participants expressed a need for culturally appropriate and user-friendly instruments for parent guidance and staff/team training on the topic of *developmental care*.

During Phase 2 a tool for parent guidance titled “*Neonatal communication intervention programme for parents*” was compiled for use by speech-language therapists and justified by participants’ roles and needs as well as current early communication intervention (ECI) literature. The programme was piloted by three participants. Certain suggestions for enhancements of the programme were made such as providing a glossary of terms, adapting the programme’s language and terminology, and providing more illustrations. The programme complied with the guiding principles for best practice in ECI (ASHA, 2008) and can therefore contribute to neonatal care of high risk infants in South Africa. Speech-language therapists and audiologists must contribute to neonatal care of high risk infants to facilitate optimal health and development and to support their families.

Key words: Early communication intervention (ECI); kangaroo mother care (KMC); neonatal communication intervention; developmental care; public health care context; neonatal intensive care unit (NICU); high risk infant.

Opsomming

Titel: Die ontwikkeling van 'n neonatale kommunikasie intervensie instrument

Navorsers: Esedra Strasheim

Studieleiers: Prof. B. Louw & Prof. A. Kritzinger

Departement: Departement Kommunikasiepatologie

Graad: M.Kommunikasiepatologie

Omvattende intervensie in die neonatale sorgeneheid behels mediese behandeling van die neonaat, sowel as ontwikkelingstoepaslike sorg en die verskaffing van leiding, berading en inligting aan die gesin wat deel is van die besluitnemingsproses rakende die baba se sorg. Neonatale kommunikasie intervensie is van uiterste belang in Suid-Afrika aangesien daar 'n hoër prevalensie van babas is wat 'n risiko het vir ontwikkelingsafwykings en aangesien die meerderheid van hierdie babas in armoede leef.

Spraak-taalterapeute vervul 'n belangrike rol in die neonatale sorgeneheid en is 'n integrale deel van die span wat betrokke is by die hoërisiko neonatale populasie. Plaaslike literatuur dui op 'n tekort aan inligting rakende die huidige dienslewering van die spraak-taalterapeut en oudioloog in neonatale sorgenehede in die Suid-Afrikaanse konteks. Vanuit 'n bate-benadering kom dit voor of die Suid-Afrikaanse populasie wat dienste in neonatale sorgenehede ontvang, unieke eienskappe het. Dit bied genoegsame geleentehede aan spraak-taalterapeute om intervensie te verskaf, solank die behandeling betyds in die neonatale sorgeneheid konteks aanvang neem.

Daar is 'n landswye inisiatief om die bewysgerigte tegniek van kangeroe moedersorg toe te pas. Spraak-taalterapeute moet dus die belang daarvan herken en kommunikasie gebaseerde terapiemateriaal ontwikkel om hierdie suksesvolle neonatale intervensie te komplementeer. Die navorsing se doel was om vas te stel hoe wyd spraak-taalterapeute en oudiologie 'n behoefte aan evaluasie en intervensie instrumente en –materiaal in hierdie konteks het. Die navorsing het verder ten doel gestel om 'n relevante terapie instrument saam te stel vir spraak-taalterapeute in die neonatale sorgenehede as 'n

moontlike oplossing vir die tekort aan relevante terapiemateriaal in die plaaslike publieke gesondheidsorgkonteks.

Die studie het beskrywende, eksplorerende navorsing behels. Gedurende Fase 1 is 'n vraelys terug ontvang van 39 spraak-taalterapeute en twee oudioloë in ses provinsies. Die data het aangedui dat deelnemers verskillende rolle in hierdie konteks vervul, wat beïnvloed was deur die omgewing, die instrumentasie en materiaal wat tot hulle beskikking was. Die meerderheid van die deelnemers was onervare, maar was vindingryk in hulle pogings om terapiemateriaal aan te pas en te ontwikkel. Deelnemers het 'n behoefte vir kultureel toepaslike- en gebruikersvriendelike instrumente en materiaal uitgedruk met die oog op oerleiding en personeel/span opleiding oor die onderwerp van *ontwikkelingstoepaslike sorg*.

Gedurende Fase 2 is 'n terapie instrument naamlik "*Neonatale kommunikasie intervensie program vir ouers*" saamgestel vir die gebruik in die neonatale sorgeenhede deur spraak-taalterapeute. Die samestelling van hierdie program is verantwoord deur die deelnemers se rolbeskrywing en behoeftebepaling van Fase 1, sowel as deur huidige vroeë kommunikasie intervensie (VKI) literatuur. Die program is deur drie deelnemers in 'n loodsstudie geëvalueer. Voorstelle vir die verbetering van die program is verskaf, naamlik die byvoeging van 'n terminologielys, aanpassing van die program se taalgebruik en terminologie en verskaffing van meer illustrasies. Die program het ooreengestem met die beginsels vir beste praktyk in VKI (ASHA, 2008) en kan daarom tot neonatale sorg van hoërisikobabas in Suid-Afrika bydra. Spraak-taalterapeute en oudioloë moet bydra tot neonatale sorg van hoërisiko neonate om sodoende optimale gesondheidsorg en ontwikkeling te fasiliteer en gesinne te ondersteun.

Sleutel terme:

Vroeë kommunikasie intervensie (VKI); kangeroe moedersorg (KMS); neonatale kommunikasie intervensie; ontwikkelingstoepaslike sorg; publieke gesondheidsorg konteks; neonatale intensiewe sorgeenheid (NISE); hoërisikobaba.

CONTENTS

CHAPTER 1

PERSPECTIVES ON THE ROLE OF THE SPEECH-LANGUAGE THERAPIST AND AUDIOLOGIST IN THE NEONATAL NURSERY

1.1 INTRODUCTION.....	1
1.2 THE ROLE OF THE SPEECH-LANGUAGE THERAPIST AND AUDIOLOGIST IN THE NICU.....	2
1.3 ECI IN THE NEONATAL NURSERY IN THE SOUTH AFRICAN CONTEXT.....	5
1.4 ENHANCING NEONATAL COMMUNICATION INTERVENTION SERVICES.....	10
1.5 CONCLUSION AND RATIONALE.....	11
1.6 DESCRIPTION OF TERMINOLOGY.....	12
1.7 CHAPTER OUTLINE.....	14
1.8 SUMMARY.....	15

CHAPTER 2

BEST PRACTICE IN NEONATAL CARE IN SOUTH AFRICA

2.1 INTRODUCTION.....	16
2.2 THEORETICAL UNDERPINNINGS FOR A NEONATAL COMMUNICATION INTERVENTION TOOL.....	19
2.2.1 Best practice in developmental care.....	19
2.2.2 ECI service delivery in South Africa.....	24
2.2.3 The population requiring developmental care.....	32
2.2.4 The team involved in neonatal care services in public hospitals...	36
2.2.5 Programmes and services in neonatal care in South Africa.....	39
2.2.6 Neonatal communication intervention: The role of the speech- language therapist.....	47



2.2.7 Neonatal communication intervention tools in South Africa.....	50
2.3 CONCLUSION.....	56
2.4 SUMMARY.....	57

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION.....	58
3.2 AIMS.....	59
3.3 RESEARCH DESIGN.....	59
3.4 RESEARCH ETHICS.....	61
3.5 PHASE 1.....	63
3.5.1 Objectives.....	63
3.5.2 Sample.....	63
3.5.2.1 Population.....	63
3.5.2.2 Criteria for the selection of participants.....	63
3.5.2.3 Selection procedures.....	64
3.5.2.4 Description of the participants.....	65
3.5.3 Materials.....	73
3.5.3.1 Cover letter.....	73
3.5.3.2 Self-designed questionnaire.....	74
3.5.3.3 Pilot study.....	81
3.5.4 Validity and reliability of the questionnaire.....	83
3.5.5 Data collection procedures.....	84
3.5.6 Data analysis and statistical procedures.....	85
3.6 PHASE 2.....	87
3.6.1 Objectives.....	87
3.6.2 Data collection procedures.....	87

3.6.3 Trustworthiness issues.....	88
3.7 CONCLUSION.....	89
3.8 SUMMARY.....	89

CHAPTER 4

RESULTS AND DISCUSSION

4.1 INTRODUCTION.....	91
4.2 RESULTS PHASE 1.....	92
4.2.1 Objective 1: To describe the perceptions of speech-language therapists and audiologists providing ECI services in provincial hospitals regarding their roles in neonatal nurseries.....	92
4.2.1.1 Screening and assessment of infants.....	92
4.2.1.2 Intervention directed at the infant and parents/caregivers.....	92
4.2.1.3 Intervention directed at staff and team members.....	99
4.2.1.4 Audiologists' perceptions of their roles in neonatal nurseries.....	100
4.2.1.5 Participants' perceptions of competence and work satisfaction.....	102
4.2.1.6 Improved future service delivery.....	110
4.2.2 Objective 2: To identify participants' needs in terms of neonatal communication intervention instruments/tools.....	115
4.2.2.1 Assessment instruments or tools.....	115
4.2.2.2 Intervention tools/materials for use with parents/caregivers.....	118
4.2.2.3 Intervention tools/materials for use with staff/team members.....	120
4.2.2.4 Audiologists' needs in terms of instruments/tools for assessment and intervention.....	122

4.2.2.5 General perceptions regarding clinical instruments/tools....	123
4.2.3 Conclusion of Phase 1.....	126
4.3 RESULTS OF PHASE 2.....	127
4.3.1 Objective 3: To select and justify a specific need of the participants in terms of neonatal communication intervention instruments/tools in the public hospital context.....	127
4.3.1.1 Justification of the selection of a specific need: speech-language therapists' needs and their roles.....	127
4.3.1.2 Justification of the selection of a specific need: current literature.....	130
4.3.2 Objective 4: To compile a preliminary instrument/tool based on the selection of one of the perceived needs of the participants....	133
4.3.2.1 Aim of the tool.....	133
4.3.2.2 Considerations for the training of adult learners.....	133
4.3.2.3 Procedures followed in the compilation of the "Neonatal communication intervention programme for parents"	135
4.3.2.4 Sequence and content of the "Neonatal communication intervention programme for parents"	137
4.3.2.5 Format of the "Neonatal communication intervention programme for parents"	142
4.3.3 Objective 5: To pre-test the "Neonatal communication intervention programme for parents"	144
4.3.4 Conclusion of Phase 2.....	149
4.4 SUMMARY.....	150

CHAPTER 5

CONCLUSION AND RECOMMENDATIONS

5.1 INTRODUCTION.....	151
5.2 SYNOPSIS OF PREVIOUS CHAPTERS.....	152
5.3 GENERAL CONCLUSIONS.....	153
5.4 IMPLICATIONS OF THE RESEARCH.....	154
5.5 CRITICAL REVIEW.....	159
5.5.1 Critical review of Phase 1.....	160
5.5.2 Critical review of Phase 2.....	162
5.6 RECOMMENDATIONS FOR FURTHER RESEARCH.....	164
5.7 FINAL COMMENTS IN CONCLUSION.....	166

REFERENCES.....	167
-----------------	-----

APPENDICES

Appendix A [i]: Ethical clearance.....	1
Appendix A [ii]: Permission from provincial departments of health...	2
Appendix B: Letter to provincial departments of health.....	8
Appendix C: Cover letter to participants.....	10
Appendix D: Questionnaire.....	12
Appendix E: Pilot study questionnaire (Phase 1).....	17
Appendix F: List of variables used in data-analysis.....	18
Appendix G: Neonatal communication intervention programme for parents.....	20
Appendix G [i]: Neonatal communication intervention programme for parents (complete programme).....	21
Appendix G [ii]: Neonatal communication intervention programme for parents Microsoft PowerPoint™ presentation.....	40
Appendix G [iii]: Handout.....	43
Appendix H: Cover letter and pilot study questionnaire (Phase 2).....	51

TABLES

Table 1.1: Selected terminology.....	13
Table 1.2: Summary of chapters.....	14
Table 2.1: Summary of the elements of developmental care.....	20
Table 2.2: Team members involved in neonatal developmental care and their roles.....	38
Table 2.3: A selection of programmes and services in the public health sector for the neonatal population in South Africa.....	40
Table 2.4: A selection of tools available for assessment of the high risk neonate’s communication and feeding abilities.....	52
Table 2.5: Locally developed neonatal communication intervention tools.....	53
Table 3.1: Number of speech-language therapists and audiologists in provincial hospitals in South Africa.....	66
Table 3.2: Content of the questionnaire.....	77
Table 3.3: Description of the pilot study.....	82
Table 4.1: Audiologists’ roles in neonatal nurseries (n = 2).....	101
Table 4.2: Proposed future improvements regarding neonatal communication intervention service delivery (n = 41).....	110
Table 4.3: Audiologists’ needs in neonatal nursery (n = 2).....	122
Table 4.4: Speech-language therapists’ needs (n = 39).....	128
Table 4.5: Speech-language therapists’ roles (n = 39).....	129
Table 4.6: Themes included in the programme.....	139
Table 4.7: Pilot study of the programme.....	145
Table 5.1: Comparison of ASHA’s guiding principles (2008 [a]) and the “Neonatal communication intervention programme for parents”.	158

FIGURES

Figure 2.1: Issues that surround the compilation of a neonatal communication intervention tool in South Africa.....	18
Figure 2.2: Roles and responsibilities of the speech-language therapist in the NICU (ASHA, 2005; Rossetti, 2001).....	48
Figure 3.1: Phases of the research project.....	60
Figure 3.2: Professional qualification (n = 41).....	67
Figure 3.3: Provinces where participants are employed (n = 40).....	68
Figure 3.4: Years experience in the government sector (n = 40).....	68
Figure 3.5: Highest qualification (n = 41).....	69
Figure 3.6: University where highest qualification was obtained (n = 40).	70
Figure 3.7: Contexts of service provision.....	70
Figure 3.8: Wards where ECI was provided.....	71
Figure 3.9: Number of speech-language therapists or audiologists in the speech-language therapy and audiology departments (n = 41)	72
Figure 3.10: Trained interpreters and/or assistants.....	73
Figure 4.1: Speech-language therapists' indication of their roles regarding screening and assessment of the infant (n = 39).....	94
Figure 4.2: Speech-language therapists' roles in intervention specifically directed at the infant and parents/caregivers (n = 39).....	97
Figure 4.3: Speech-language therapists' roles in intervention specifically directed at staff and team members (n = 39).....	99
Figure 4.4: Participants' perceptions of competence in neonatal nursery (n = 41).....	103
Figure 4.5: Participants' reasons for competence (n = 41).....	103
Figure 4.6: Participants' enjoyment of their work in neonatal nursery (n = 41).....	105
Figure 4.7: Needs regarding assessment instruments/tools (n = 39).....	117
Figure 4.8: Needs regarding intervention tools/materials specifically focused on parents or caregivers (n = 39).....	119

Figure 4.9: Needs regarding intervention tools/materials focused on staff/team members (n = 39).....	121
Figure 4.10: Schematic representation of the content of the programme.	138
Figure 5.1: Implications of the research.....	155
Figure 5.2: Strengths and limitations of Phase 1.....	160
Figure 5.3: Strengths and limitations of Phase 2.....	162

ABBREVIATIONS

- ABR - Auditory brainstem response
- AIDS - Acquired immunodeficiency syndrome
- ASHA - American Speech-language and Hearing Association
- BFHI - Baby friendly hospital initiative
- CPD - Continued professional development
- ECI - Early communication intervention
- EI - Early intervention
- FASD - Fetal alcohol spectrum disorder
- FEFARI - Feeding evaluation form for at-risk infants
- HIV - Human immunodeficiency virus
- HPCSA - Health professions council of South Africa
- JCIH - Joint commission on infant hearing
- KMC - Kangaroo mother care
- NHCU - Neonatal high care unit
- NICU - Neonatal intensive care unit
- NIDCAP - Newborn individualised developmental care and assessment programme
- OAE - Oto-acoustic emission
- OCI - Observation of communicative intent
- PHC - Primary health care
- PMTCT - Prevention of mother to child transmission
- PPIP - Perinatal problem identification programme
- PPP - Pretoria pasteurisation project
- ROP - Retinopathy of prematurity
- SASLHA - South African speech-, language- and hearing association
- SLT & A - Speech-language therapist and audiologist
- UNICEF - United nations children's fund
- WHO - World health organisation