Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

## Augmentative and Alternative Communication in Intensive Care Units in New Zealand: Experiences of Healthcare Professionals

A thesis presented in partial fulfillment of the requirements for the degree of

Master of Speech Language Therapy

at Massey University, Albany

**NEW ZEALAND** 

Alison Kaye Paulin

2016

## Contents

List of Figures and Tables	v
Acknowledgements	vi
ABSTRACT	viii
Chapter 1. INTRODUCTION	1
1.1. Background	1
1.2. Rationale and Purpose of the Project	3
1.3. The Structure of the Thesis	3
Chapter 2. LITERATURE REVIEW	4
2.1. Augmentative and Alternative Communication	4
2.2. ICU Context	5
2.2.1. Changes	7
2.3. Effective Communication in Healthcare Settings	7
2.3.1. Impact on Physical Wellbeing	8
2.3.2. Impact on Psychological Wellbeing	8
2.3.3. Standards for Effective Communication in Healthcare Setti	ngs10
2.3.4. Summary	11
2.4. Communication in the ICU	11
2.4.1. Patients' Perspectives	11
2.4.2. Family Members' Perspectives	13
2.4.3. HCPs' Perspectives and Communication Strategies Used.	
2.4.4. Summary	17
2.5. AAC in the ICU: Communication Solutions	
2.5.1. Oral Communication Options	
2.5.2. Augmentative and Alternative Communication	18
2.5.3. Implementation	29
2.6. The New Zealand Context	33
2.7. Conclusion	34
Chapter 3. METHODS	35
3.1. Research Questions	35
3.2. Method	35
3.2.1. Qualitative Methods	36
3.2.2. Rationale for Method Chosen	37

3.3.	Participant Recruitment	. 40
3.4.	Data Collection	. 42
3.4.1	I. Interview Guide Development	. 42
3.4.2	2. Pilot Interview	. 43
3.4.1	Semi Structured Interviews	. 43
3.4.2	2. Preparation of Data for Analysis	. 44
3.5.	Data Analysis	. 45
3.6.	Ethical Considerations	. 48
3.7.	Summary	. 49
Chapte	er 4. RESULTS	. 50
4.1.	Participant and DHB Information	. 50
4.2.	Experiences Communicating with Patients who are Unable to Speak	. 52
4.2.1	Communication Breakdown	. 52
4.2.2	2. Limited Communication Attempts	. 52
4.2.3	3. Impact of Communication Difficulties	. 55
4.2.4	l. Summary	. 59
4.3.	AAC Tools and Strategies used in ICUs	. 59
4.3.1	Expressive Strategies	. 60
4.3.2	2. Comprehension Strategies	. 63
4.3.3	3. Access Modes	. 63
4.3.4	l. Summary	. 64
4.4.	Factors affecting Communication	. 64
4.4.1	Hospital and HCP related Factors	. 65
4.4.2	2. Patient Related Factors	. 71
4.4.3	3. Summary	. 75
4.5.	Differences between DHBs	. 75
4.6.	Differences between HCPs	. 77
4.7.	Training	. 78
4.8.	Summary	. 79
Chapte	er 5. DISCUSSION	. 80
5.1.	Communication Difficulties Experienced by HCPs	. 81
5.1.1	Communication Breakdown	. 81
5.1.2	2. Limited Communication Attempts	. 82
5.2.	Impact of Communication Difficulties	. 83

5.2.1.	Negative Psychological Consequences for Patients and HCPs	84
5.2.2.	Lack of Patient Consent	84
5.3. AA	AC Tools and Strategies used in NZ ICUs	85
5.3.1.	Expressive Strategies	85
5.3.2.	Access Modes	88
5.3.3.	Comprehension Strategies	90
5.4. Ba	rriers and Facilitators of Effective Communication	91
5.4.1.	Hospital and HCP Factors	91
5.4.2.	Patient factors	95
5.5. Dif	fferences between DHBs	97
5.6. Tra	aining	98
Chapter	6. CONCLUSION	99
6.1. Pu	rpose and Rationale	99
6.2. Lir	nitations	100
6.2.1.	Limited Number of Participants and DHBs	100
6.2.2.	Self-Selection Bias	100
6.2.3.	Professions	101
6.2.4.	Single data source	101
6.2.5.	Bias of self-report	101
6.3. Im	plications for Clinical Practice	102
6.3.1.	Training	102
6.3.2.	Availability of AAC tools	104
6.3.3.	Team practice	105
6.4. Im	plications for Future Research	107
6.5. Co	oncluding Comments	108
REFERE	NCES	109
Appendi	x A	125
Appendi	х В	126
Appendi	x C	129
Annendi	x D	131

## **List of Figures and Tables**

Figure 3-1: Example of coding process	47
Figure 4-1: HCP Factors affecting communication	66
Table 3-1: Characteristics of DHBs	40
Table 3-2: Alterations to interview guide following pilot interview	44
Table 4-1: Participant attributes	51
Table 4-2: DHB characteristics	51
Table 4-3: Expressive strategies reported as used	61
Table 4-4: Access modes reported as used	63

## **Acknowledgements**

Firstly, I wish to acknowledge the nurses and SLTs who participated in this project. I could not have done this without your willingness to share your experiences and your practice so fully. And thanks are also due to those who assisted me in obtaining research approval and recruiting participants at the various DHBs.

I wish to thank my supervisors, Dr. Sally Clendon and Assoc. Prof. Helen Southwood. To my primary supervisor, Sally, I could not have completed this thesis without your unwavering support, your steady guidance and your cheery voice beaming into my home via Skype. To my secondary supervisor, Helen, your knowledge and useful feedback were always appreciated. To both of you, your editing knives were called into action far too much! I also wish to acknowledge Ann Smaill from Talklink Trust, and Bill Fowler and John Trainor, whose stories inspired this research.

To all of my family: I am so grateful to you - Matt who encouraged me to take on this challenge and supported me throughout it, taking on extra responsibilities in the last few months to enable me to focus on it, and even stepping in to fight my battles with Word during the last week. Felix and Ruby whose routines and time with Mum were interrupted so often over the past year. My parents, sisters and all of my extended family whose support is always there.

To Kate, who has just added *editing references* to the growing list of reward-free friend tasks she has undertaken to help me, I'm eternally grateful. To my good friends Celeste, Sally and Alisone who put up with my distraction and my rantings over the past year – Thank you! Your friendship is more important to me than I ever manage to say.

Also thanks are due to Massey University, for assistance in funding those key tools of research that made such a difference. And to John, for the hours of transcription you completed on my behalf.