

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.

**Factors contributing to paediatric tube feeding dependence in New Zealand:  
The Speech-language therapy perspective.**

**A thesis presented in partial fulfilment of the requirements for the degree of**

**Master of Speech and Language Therapy**

**at**

**Massey University, Albany, New Zealand**

**Emily Amy Jones**

**2016**

## Abstract

Tube feeding dependency can have serious repercussions for children and their families. Most research relates to intervention programmes for tube withdrawal/weaning onto oral feeding. However, there is limited research into factors contributing to tube feeding dependency. Researchers have found failed or slow weaning/transitioning from tube to oral feeding is more likely after the age of five. In New Zealand the highest number of children who remain tube dependent but could transition to oral feeding are over five years of age. Speech–language therapists (SLTs) are one of the main professions involved in managing these children.

This two-phase study aimed to determine the SLTs' perspective of factors contributing to feeding tube dependency in children. This study used a mixed method approach. Forty-three SLTs participated in an online survey and ten of these participants were interviewed.

Two interlinking themes were found as contributing factors to tube feeding dependency in children. They were: (1) *Medicalisation of tube fed children in infancy as a root cause of tube feeding dependency*. Sub themes included the following: Medical emphasis on weight gain; parents and caregivers influence whether a child remains tube dependent; parents giving misleading information to maintain tube feeding and prolonged NGT feeding. (2) *Fragmentation of the tube fed child's continuity of care*. Sub-themes include the following: The need for planning tube withdrawal at the time of insertion, insufficient clinical time, funding issues, the need for intensive service at the time of tube weaning, clinician confidence in the education setting and the normalisation of tube feeding by school age. These themes and sub-themes influence tube feeding dependency in New Zealand, according to the perspective of SLTs.

This research highlights the need for further exploration of these factors when the tube is first inserted to prevent dependency and allow the transitioning of children to oral foods as early as possible.

## Acknowledgements

Firstly and foremost, I would like to thank the speech-language therapists who shared their time and thoughts, as without them this study would not have been possible. I am hopeful that the findings of this study will facilitate wider discourse for the children who are feeding tube dependent and help them reach their oral feeding potential.

Secondly, to the staff and past and present students of the Speech and Language Therapy Programme at Massey University, I am extremely fortunate to work with you all and so proud to be part of such a first class programme.

To the best supervisors a student could ask for. First, I would not have been able to complete this journey without the encouragement and belief of Associate Professor Helen Southwood. I cannot thank you enough Helen for your unfailing support and guidance including your attention to detail and writing skills. To my second supervisor Dr. Catherine Cook, who has introduced and guided me through the world of qualitative methodology. You are a skilled interviewer and analyser and have inspired me to advocate further for these children and their families. I would also like to thank Vanessa van der Ham at Teaching and Learning at Massey, who has been another mentor. Your editing skills have been invaluable.

To my family who have supported my postgraduate ambitions. To my husband Stevo, who has been my greatest advocate and supporter and to my daughters Isabel and Felicity who don't quite know what I have been doing for two years but have given me some extra time when I have needed it. Also to my parents Susan and Doug Bailey for having the girls while I completed the final document.

A final acknowledgement is to the Institute of Education at Massey University including the Graduate Research Fund and Pathways Scholarship for the financial support I have received.

## Table of contents

<b>ABSTRACT .....</b>	<b>I</b>
<b>ACKNOWLEDGEMENTS.....</b>	<b>II</b>
<b>TABLE OF CONTENTS.....</b>	<b>III</b>
<b>LIST OF FIGURES.....</b>	<b>VII</b>
<b>LIST OF TABLES .....</b>	<b>VII</b>
<b>CHAPTER ONE- INTRODUCTION.....</b>	<b>8</b>
<b>What is tube feeding? .....</b>	<b>8</b>
<b>Potential risk of over utilisation.....</b>	<b>8</b>
Problems associated with tube feeding in children .....	8
Tube feeding dependency in children.....	9
The Speech-language therapists' .....	9
Aim of study .....	9
<b>CHAPTER TWO-LITERATURE REVIEW.....</b>	<b>11</b>
<b>Factors contributing to tube feeding dependency, preventing transition to oral feeding .....</b>	<b>11</b>
Parent-Child Interaction .....	11
Typical feeding development .....	11
The three stages of feeding development .....	12
Tube feeding and maternal grief.....	13
Parental anxiety and subsequent mealtime behaviour towards their child: .....	13
Appetite dysregulation, reflux, and vomiting .....	14
Type of feeding tube .....	15
Oral Sensory Defensiveness .....	16
<b>Interventions for transitioning from tube to oral feeding-“Tube weaning” .....</b>	<b>17</b>
<b>Factors influencing intervention effectiveness for transitioning to oral feeding. ....</b>	<b>19</b>
<b>Research Question.....</b>	<b>20</b>
<b>CHAPTER 3- METHODOLOGY .....</b>	<b>21</b>
<b>Study Design: Sequential explanatory approach.....</b>	<b>21</b>
What is mixed methods research?.....	21
<b>Worldview .....</b>	<b>21</b>
<b>Participants: .....</b>	<b>22</b>

Participant recruitment.....	22
<b>Survey.....</b>	<b>23</b>
Pilot Survey.....	25
Data Analysis .....	25
<b>Semi-structured interviews.....</b>	<b>25</b>
Interview participants .....	25
Interview questions.....	25
Data analysis .....	26
<b>Limitations of Study.....</b>	<b>27</b>
<b>Ethical Considerations .....</b>	<b>28</b>
<b>Summary .....</b>	<b>28</b>
<b>CHAPTER 4- QUANTITATIVE RESULTS.....</b>	<b>29</b>
<b>Data cleaning.....</b>	<b>29</b>
<b>Demographic Questions.....</b>	<b>29</b>
<b>Participant caseload variables .....</b>	<b>29</b>
<b>Table 1: Demographic data of SLTs working with tube fed children .....</b>	<b>30</b>
<b>Table 2: Caseload information of SLTs working with tube fed children .....</b>	<b>31</b>
<b>Management of tube fed children .....</b>	<b>33</b>
Responses to perspectives about tube feeding dependency.....	33
<b>Summary .....</b>	<b>37</b>
<b>CHAPTER 5- QUALITATIVE RESULTS .....</b>	<b>38</b>
<b>Results from the semi-structured interviews .....</b>	<b>38</b>
Qualitative Validity.....	39
Member checking .....	39
<b>Interview themes.....</b>	<b>39</b>
<b>Parents are integral to outcomes.....</b>	<b>40</b>
Tube feeding interfering with bonding and maternal identity .....	40
Parental and child stress at mealtimes .....	41
Reluctance to stop tube feeding, due to weight loss concerns .....	41
Parental dependence on tube feeding.....	42
The need for psychological input .....	43
Parents seeking intensive support .....	44
Barriers to family meal culture.....	45
Cultural differences.....	46
Summary .....	47

<b>Developmental and structural obstacles for school-aged children</b> .....	<b>47</b>
Normalisation of tube feeding by school age .....	48
The increase in medically fragile non-funded children for child development caseloads .....	48
Change of service delivery as child gets older: .....	50
Summary .....	51
<b>Service Delivery Issues</b> .....	<b>51</b>
The impact of philosophical differences between health and education services for tube dependent children .....	51
Confidence of Education support staff skills to support oral feeding .....	53
Challenges for the SLT to advocate for tube dependent children .....	54
Lack of joint planning and communication across the MDT for the tube fed child .....	55
Planning for transition to oral feeding in the future:.....	56
Summary .....	57
<b>Tube feeding and negative sequelae</b> .....	<b>57</b>
Lack of appetite .....	57
Pain.....	60
Summary .....	61
<b>Chapter Summary</b> .....	<b>61</b>
<b>CHAPTER 6 - DISCUSSION AND CONCLUSIONS</b> .....	<b>62</b>
<b>Medicalisation as a root cause of tube feeding dependency</b> .....	<b>62</b>
<b>Fragmentation of the care pathway for the tube fed child</b> .....	<b>69</b>
<b>Significance of Study</b> .....	<b>75</b>
<b>Implications of findings</b> .....	<b>75</b>
<b>Practical Applications: Prevention Strategies</b> .....	<b>76</b>
Cue based feeding in NICU.....	76
Planning to remove the tube from the time of insertion .....	76
Encourage oral exploration and scheduled mealtimes.....	76
Limit NGT time .....	77
Support for professionals to encourage oral feeding potential.....	77
<b>Limitations of study</b> .....	<b>78</b>
<b>Directions for future research</b> .....	<b>78</b>
<b>Final Thoughts</b> .....	<b>79</b>
<b>REFERENCES</b> .....	<b>80</b>
<b>Appendix A: Information sheet for survey</b> .....	<b>88</b>
<b>Appendix B: Information sheet for interview component</b> .....	<b>90</b>
<b>Appendix C: Interview consent form</b> .....	<b>90</b>

**Appendix D: Interview Schedule for Semi structured Interviews .....92**

**Appendix E: Transcribers Confidentiality Agreement .....94**

**Appendix F: Human Ethics Approval .....95**

**Appendix G: Survey Questions.....96**



## List of Figures

Figure 1: Sequential Explanatory Design (adapted from Creswell & Plano Clark, 2011, pg. 64) ..... 24

## List of Tables

Table 1: Summary of demographic data of 43 participants .....	30
Table 2: Caseload information of 43 SLT participants .....	31
Table 3: Management information of tube fed children .....	32
Table 4: Attitudinal responses of participants on tube feeding dependency .....	35
Table 5: Interview participants .....	38