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.

When Motherhood Beckons: an exploration of the transition to Motherhood for HIV positive Women

by

Amanda Hinks

A thesis

presented in partial fulfillment of the requirements

for the degree of

Masters in Philosophy

Massey University, Manawatu New Zealand

2010

Acknowledgements

I would like to acknowledge Dr Cheryl Benn and Dr Jeanie Douche of Massey University, New Zealand and thank them both for their patience and valuable contribution to the compilation and completion of this thesis.

I would like acknowledge the support of the Taranaki District Healthboard, Ministry of Health and particularly my manager Dianne Herbert for her support. I would like to extend my gratitude to Honor Lymburn for her support in the completion of this thesis.

I would like to thank the women who made this study possible; Jane Bruning at Positive Women in Auckland, Deborah, Susan, Marama and their beautiful babies. I am deeply grateful to you all for giving me your time and sharing your stories.

Dedicated to all the HIV positive mothers and babies whom I have cared for and those I have yet to meet.

ABSTRACT

The aim of the research was to explore the transition to motherhood for women who have been diagnosed with HIV before pregnancy. Pregnancy is a time of adjustments for all women; socially psychologically and physically, the midwife has a fundamental role in supporting the woman to make a successful transition. HIV is increasing in New Zealand's heterosexual population and with the national introduction of antenatal HIV testing midwives the diagnoses made will increase. Communities and health professionals need to hear about women's experiences and recommendations from research about how best to provide individualised care for both mother and baby.

This small research study was undertaken in 2008. Three women living in New Zealand with a positive HIV diagnosis were interviewed about their transition to motherhood. The babies of mothers in this study were aged between 3 and 18 months and the women knew their HIV diagnosis prior to pregnancy. The women spoke candidly about their experience of becoming pregnant, being pregnant and the transition to motherhood over the subsequent months of their babies' lives. Three chapters present the themes from the women's narratives; Chapter Four details the journey to becoming a mother. The themes identified were the desire to become a mother; "working hard for this baby"; maternal-infant attachment and "becoming a mother changes everything." The themes in Chapter Five focus on how the women manage stigma and disclosure of their condition. The theme of managing disclosure in their personal world to family, friends and the child is identified. The maintenance of privacy and confidentiality is a theme arising from their step into the health service. In Chapter Six the theme of disempowering behaviours and

perceived lack of evidence based care is discussed. The women describe how knowledge of HIV positive mothers was lacking as some health professionals queried "why aren't you breastfeeding?" The women identified sources of support and knowledge which used to address the imbalance of power they felt whilst engaging with health professionals and wider society.

In conjunction with midwives and other health professionals, the communities in which the women live are an integral component of supporting women to become mothers.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	vi
ABSTRACT	vi-vi
TABLE OF CONTENTS	vi
CHAPTER 1: ORIENTATION TO THE STUDY	1
INTRODUCTION	1
BACKGROUND TO THE STUDY	2
ORIENTATION OF THE RESEARCHER	2
AIM OF THE STUDY	3
REVIEW OF THE CHAPTERS	3-5
SUMMARY	5
CHAPTER TWO: LITERATURE REVIEW	6
INRODUCTION	6
THE LITERATURE SEARCH	6-8
THEMES IDENTIFIED FROM THE LITERATURE	8
THE DESIRE FOR MOTHERHOOD	8-15
THE CONTEXT OF BECOMING A MOTHER WITH HIV	15-18
MOTHERHOOD AS A COPING MECHANISM	18-21
THE THEORY OF THE TRANSITION TO MOTHERHOOD	21-23
ROUTE OF WOMAN'S HIV INFECTION	23-24

HAVING HOPE	24-25
HEALTH SERVICES ENVIRONMENT	25-26
SUMMARY	26-27
CHAPTER THREE: RESEARCH METHODOLOGY	28
AND METHOD	
INTRODUCTION	28
METHODOLGY AND METHODS	28-30
ETHICAL CONSIDERATIONS	30-31
PARTICIPANT RECRUITMENT	31-34
INCLUSION CRITERIA	34-36
INFORMED CONSENT	36
ACCOUNTABILITY OF THE RESEARCHER	37
CONFIDENTIALITY	37
RESEARCH AS A PARTNERSHIP	38
PROMOTION OF THE INTERESTS OF HIV POSITIVE WOMEN AND	39
MOTHERS	
ADVOCACY	39
AVOIDANCE OF HARM	40
CONFLICT OF INTEREST	41
METHOD OF DATA COLLECTION	41-42
THE INTERVIEW PROCESS	42
LOCATION OF INTERVIEWS	43-44
DATA ANALYSIS	44-45
THEMATIC ANALYSIS	46
RIGOUR OF THE RESEARCH	47
TRUSTWORTHINESS	48
CREDIBILITY	49
AUDITABILITY	50
FITTINGNESS	50

CONFIRMABILITY	50
SUMMARY	51
CHAPTER FOUR: BECOMING A MOTHER	52
INTRODUCTION	52-53
THE DESIRE FOR MOTHERHOOD	53-57
THE EFFECT OF HIV ON INTIMATE RELATIONSHIPS	57-62
BECOMING PREGNANT	62-64
ENSURING SAFE PASSAGE; "WORKING HARD FOR THIS BABY"	64-65
"I HAVE GONE THROUGH SO MUCH TO GET HIM HERE HEALTHY"	65-68
MATERNAL INFANT ATTACHMENT "HE WAS THE CHILD I THOUGHT	68-72
I WOULD NEVER HAVE"	
"BECOMING A MOTHER CHANGES EVERYTHING"	72-77
SUMMARY	77
CHAPTER FIVE: STIGMA AND DISCLOSURE	79
INTRODUCTION	79
STIGMA	79-83
DISCLOSING TO LOVED ONES	83-88
DISCLOSING TO FRIENDS	88-89
MANAGING DISCLSOURE TO THEIR CHILDREN	89-91
PUBLIC DISCLOSURE	91-93
SUMMARY	93
CHAPTER SIX: KNOWLEDGE IS POWER	94
INTRODUCTION	94
DISEMPOWERING BEHAVIORS	95-98
"I DIDN'T HAVE AN OPTION"	98-
	102
"WHY AREN'T YOU BREASTFEEDING?"	102-

	104
"KNOWLEDGE IS POWER"	104-
	105
SUMMARY	105
CHAPTER SEVEN: DISCUSSION AND	107
CONCLUSION	
INTRODUCTION	107
THE RESEARCH QUESTION	107
KEY FINDINGS	108
THE TIMING OF MOTHERHOOD	108
THE EFFECT OF STIGMA ON THE HIV POSITIVE WOMAN'S TRANSITION	108-
TO MOTHERHOOD	109
IMPLICATIONS FOR HEALTHCARE PRACTITIONERS AND MIDWIVES	109-
	110
IMPROVING THE CONDITIONS FOR MOTHER AND BABY ATTACHMENT	110-
	111
IMPLICATIONS FOR EDUCATION	111-
	112
LIMITATIONS OF THE STUDY	113
RECOMMENDATIONS FOR FURTHER RESEARCH	112
CONCLUSION	112-
	113
APPENDIX A: RESEARCH CONSENT FROM	114
MULTIREGIONAL ETHICS COMMITEE	
APPENDIX B: LETTER OF RECOMMEDNATIONS	115
AND COMMENTS FROM MAORI HEALTH PROVIDER	
APPENDIX C: ADVERTISEMENT FOR POTENTIAL	116

PARTICPANTS	
APPENDIX D: ARTICLE FOR POSITIVE WOMEN INC.	117
NEWSLETTER	
APPENDIX E: PARTICIPANT INFORMATION SHEET	118
REFERENCES	120-
	130