Children of parents with mental illness: Parental disclosure, children’s illness beliefs and the development of a shared understanding of mental illness in the family.

Brooke Ferguson

School of Psychology
The University of Adelaide

Submitted in partial fulfilment of the requirements for the Combined Master of Psychology (Clinical)/ Doctor of Philosophy

July 2011
Declaration

I, Brooke Ferguson, certify that this work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying, subject to the provisions of the Copyright Act 1968.

I also give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library catalogue, the Australasian Digital Theses Program (ADTP) and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

______________________________
Brooke Ferguson
Acknowledgements

My thanks go to the many people who have made this thesis possible.

To the parents and children of this study, my sincerest gratitude. You welcomed me into your homes and you talked about details of your lives with me, an act which I know could not have been easy. Your stories have affected me deeply and will always stay with me.

To my primary supervisor, Lisa Kettler, thank you so much for being exactly the supervisor, confidant and friend that I needed on this journey. You showed faith in this project, and in me, when the challenges seemed insurmountable.

To Helen Winefield, my secondary supervisor, my thanks to you for being a willing (and very quick!) reader of drafts and provider of thoughtful comments.

My thanks to all of the COPMI and COMIC people who helped along the way. It was so inspiring to find such a supportive community of researchers, advocates, consumers and carers. Your support across the period of my candidature was invaluable. Special thanks to Vicky Cowling, Paola Mason and Nerrelle Goad who approached their networks to help recruit participants. This project would not have been possible without them.

To Nette, Brian, Gemma and Lachlan, if not for you I would not have finished school, let alone spent a great deal of my life at University. You took me in without question and each shared your home and your family with me. The disadvantages of being a child of a parent with mental illness follow through to adulthood. So many major milestones are difficult without a parent for guidance and help. You’ve been there for all of my milestones and have made sure I was never at a disadvantage. Your relationship and support with William is the greatest gift.

To Nick, the ultimate study in resilience. I’ve always admired your humour, compassion and success in the face of adversity. Thanks for your support and encouragement. To Callie who can always be counted on for a cup of tea, a pep talk and a reminder of what is good in life.
To the Cunningham, Heathfield and Ferguson families who danced with, sang to, looked for fairies with, delighted in, played guitar with, loved, read to and snuggled with William while I was working. In particular to Nette for being so willing to have your bubba on all of your days off and for being such a wonderful stand-in for me. To Jessica for taking such good care of Will so that I could write knowing he was happy.

To the friends who provided support, encouragement and love during the writing of this thesis. To Kathy and Nicole for being in the unique position to provide me with advice on all things academic, professional and personal. I feel so lucky to have such great women in my life. To Alex who has been there for so much of the learning that has happened outside of this PhD. To Scott who joined this journey towards the end and who has been a great office-mate and an even better friend. To Jo and Victoria for providing support and rational thought when I needed it.

Finally, to Ben and William, for your support and patience. Ben, I am so appreciative of the sacrifices made in order for me to combine the PhD, Masters and motherhood. You have believed in this project since it started and your pride has been unwavering. Your support, proof reading, crisis formatting, tea making and fathering has made this journey far easier than it could have been. To William, my beautiful funny boy, for being the ultimate motivation to complete this.
# Table of Contents

Declaration ....................................................................................................................................................... iii
Acknowledgements ............................................................................................................................................... v
**Table of Contents** ........................................................................................................................................ vii
List of tables .................................................................................................................................................... xi
**Table of figures** ............................................................................................................................................ xii
Abstract .......................................................................................................................................................... xiii

## Chapter One: Broad literature review and location of the present thesis ....................................................... 1
1.1 Clarification of terms which are used frequently within this thesis ...................................................... 1
1.2 The existence of COPMI .......................................................................................................................... 2
1.3 Prevalence estimates of parents with mental illness and their children .............................................. 3
1.4 Effect of mental illness on parenting ....................................................................................................... 5
1.4.1 What the research says about parenting with mental illness ........................................................ 5
1.4.2 What parents say about parenting with mental illness................................................................... 8
1.5 Effect of parental mental illness on children ......................................................................................... 8
1.5.1 Detrimental effects .......................................................................................................................... 9
1.5.2 Detrimental effects for adult children of parents with mental illness .......................................... 12
1.6 Resilience in children of parents with mental illness .......................................................................... 13
1.6.1 Fixed protective factors ................................................................................................................. 14
1.6.2 Protective factors amenable to intervention ................................................................................. 16
1.7 The experience of being the child of a parent with mental illness .................................................... 18
1.8 Children’s lack of understanding of mental illness ............................................................................. 19
1.9 The importance of educating children about their parent’s mental illness ......................................... 21
1.10 Educating children about parental mental illness; what do parents think? .................................. 24
1.11 Gaps in the literature ........................................................................................................................... 25
1.12 Research questions ............................................................................................................................. 26
1.13 Overview of thesis ............................................................................................................................... 26

## Chapter Two: Methodology ............................................................................................................................. 29
2.1 Ethics approval...................................................................................................................................... 30
2.2 Participants............................................................................................................................................ 31
2.3 Recruitment ........................................................................................................................................... 31
2.4 Procedure .............................................................................................................................................. 32
2.4.1 Recruitment procedure .................................................................................................................. 32
2.4.2 Interview location ........................................................................................................................... 34
2.4.3 Engagement ................................................................................................................................... 34
2.4.4 Interviews with children ................................................................................................................. 36
2.4.5 Length of interviews ....................................................................................................................... 37
2.5 Sample characteristics .................................................................................................................................. 37
2.5.1 Parent demographic details.................................................................................................................. 37
2.5.2 Child demographic details.................................................................................................................... 45
2.6 Interview schedule .................................................................................................................................. 47
2.6.1 The use of semi-structured interviews............................................................................................... 47
2.6.2 The theoretical framework guiding the interview questions and analysis ....................................... 49
2.6.3 The specific questions asked within the present study .................................................................. 52
2.7 Data analysis .......................................................................................................................................... 53
2.7.1 Data collected for this thesis which is not included .......................................................................... 59
2.8 Ethical considerations ............................................................................................................................. 60
2.9 Motivation behind the current research ............................................................................................... 62

Chapter Three: Study one – Parents’ ideas about disclosing mental illness to their children ............. 63
3.1 Parental view of educating children about mental illness, what is known so far ............................. 63
3.2 What we know about parental views on explaining other sensitive topics ..................................... 65
3.3 The need for research into parental view of explaining mental illness .............................................. 68
3.4 Aim ......................................................................................................................................................... 69
3.5 Method ................................................................................................................................................... 69
3.6 Analysis and Discussion Part I: The process of disclosure from the parent perspective .............. 71
3.6.1 At what age should illness be explained? ......................................................................................... 71
3.6.2 Beliefs about whether children know about their parent’s illness ................................................. 74
3.6.3 Beliefs about who told children about their parent’s illness ......................................................... 74
3.6.4 How parents talked to children about parental mental illness ....................................................... 89
3.7 Analysis and Discussion Part II: Parent perspectives on non-disclosure ........................................ 108
3.7.1 Reluctance to tell due to child ......................................................................................................... 109
3.7.2 Reluctance to tell due to parent ...................................................................................................... 119
3.7.3 Resources to help disclose ............................................................................................................. 129
3.8 Summary ............................................................................................................................................. 145

Chapter Four: Review – Children’s understanding of mental illness ................................................. 149
4.1 Children’s understanding of physical illness ......................................................................................... 149
4.2 Differences between mental and physical illness ............................................................................... 150
4.3 The need for synthesis .......................................................................................................................... 151
4.4 Aim ....................................................................................................................................................... 152
4.5 Parameters of the literature included ................................................................................................. 152
4.6 Review structure .................................................................................................................................. 154
4.7 Review .................................................................................................................................................. 155
4.7.1 Identity of mental illness ................................................................................................................... 156
4.7.2 Cause of mental illness .................................................................................................................... 162
4.7.3 Treatment and consequence of mental illness ............................................................................... 168
Chapter Five: Study Two, Part I – Children’s ideas about their parent’s illness, symptoms, cause, treatment, timeline and consequences for the family

5.1 Aim

5.2 Method

5.3 Analysis and discussion

5.3.1 Identity of mental illness

5.3.2 Cause of mental illness and what can trigger a parent’s symptoms

5.3.3 Treatment for mental illness

5.3.4 Timeline of mental illness

5.3.5 Consequences of mental illness

5.4 Summary

Chapter Six: Study Two, Part II – Do children think they have enough information and how is information transmitted?

6.1 Aim

6.2 Analysis and Discussion

6.2.1 Children’s ideas about their understanding of their parent’s illness: do children think they need more information?

6.2.2 Where does information about mental illness come from?

6.2.3 Do children talk to their teachers, friends or siblings about their parent’s mental illness?

6.2.4 Where would you go to get more information about your parent’s mental illness?

6.3 Summary

Chapter Seven: Study three – Family communication and understanding of mental illness

7.1 Literature examining familial perceptions of illness

7.1.1 Literature examining familial beliefs about mental illness

7.2 The current study

7.3 Aim

7.4 Analysis

7.4.1 Family one

7.4.2 Family two

7.4.3 Family three

7.5 Discussion

7.5.1 Family one

7.5.2 Family two

7.5.3 Family Three

7.5.4 Overall discussion
Chapter Eight: Summary and conclusions ................................................................. 359

8.1 Reorientation to the rationale behind the current research ........................................ 359

8.2 Summary of current research ..................................................................................... 360

8.2.1 Study one: Parents’ ideas about disclosing their illness to their children .......... 360

8.2.2 Study Two, Part I: Children’s ideas about their parent’s illness; symptoms, cause, treatment, timeline and consequences for the family ................................................................. 361

8.2.3 Study Two, Part II: Do children think they have enough information and how is information transmitted? .................................................................................................................. 362

8.2.4 Study Three: Family communication and understanding of mental illness ............ 362

8.3 Key findings of the current body of work ..................................................................... 363

8.4 Summary of key clinical implications ....................................................................... 365

8.5 Strengths and limitations of the current study ............................................................ 368

8.6 Recommendations for future research ..................................................................... 372

8.7 Conclusion ................................................................................................................. 375

References ....................................................................................................................... 377

Appendices ......................................................................................................................... 396
List of tables

Table 1 Common Behavioural Manifestations of Symptoms and their Impact on COPMI
(Adapted from the table by Duncan and Reder; 2003, p.199)..................................................7

Table 2 Range of Mental Illnesses Identified By Parent Participants.................................38

Table 3 Demographic Details and Extract ID for Parent Participants.................................44

Table 4 Demographic Details and Extract ID for Child Participants.................................46

Table 5 Studies Examining the Identity of Mental Illness.................................................156

Table 6 Studies Exploring the Cause of Mental Illness....................................................162

Table 7 Studies Examining Treatments for Mental Illness................................................168

Table 8 Studies Examining the Length of Mental Illness..................................................172

Table 9 Studies Examining Sources of Information.........................................................174
Table of figures

Figure 1. Diagram of the studies included within this thesis .................................................................29
Figure 2. The age at which parents believed a child should be told about mental illness .......71
Figure 3. The range of responses parents gave for the question regarding who told their child about their parent’s mental illness ........................................................................................................75
Figure 4. The three main approaches to explaining mental illness to children.................................95
Figure 5. The themes developed from parents’ responses when discussing the difficulty with disclosing mental illness ......................................................................................................................109
Figure 6. Resources to help with parental disclosure of mental illness. ........................................129
Figure 7. The symptoms described by children in order from most to least endorsed. ........190
Figure 8. Children’s perception of cause of their parent’s mental illness ........................................210
Figure 9. Children’s ideas about what could help their parent’s illness or symptoms ................226
Figure 10. Children’s ideas about how long mental illness will last ................................................244
Figure 11. Children’s ideas about how mental illness affects the family .........................................250
Figure 12. The range of responses to the question of whether children think they understand their parent’s illness ........................................................................................................266
Figure 13. Themes developed in relation to the question “Where does information come from?” ........................................................................................................................................274
Figure 14. The number of children who talk to siblings, friends or teachers about their parent’s illness ........................................................................................................................................287
Figure 15. The main themes developed from answers to the question of where children would find further information about mental illness. ........................................................................302
Abstract

There is widespread agreement that children should be educated about a parent’s mental illness. For this to occur there are a number of areas which require further research. To date, little is known about what parents themselves think about the disclosure of mental illness to their children. It is also unclear how the process of disclosure occurs in families with mental illness. Children's own knowledge of parental mental illness has not been systematically explored and it is not known what children know about aspects of their parent’s illness. This thesis explored how families, where a parent has mental illness, discuss or do not discuss a parent’s mental illness. This was explored from the perspective of different family members, including children whose parent has mental illness, the parent with mental illness, the partner of a parent with mental illness, ex-partners of parents with mental illness and step parents of children who have a parent with mental illness.

Study One was an explorative qualitative study which aimed to examine parental beliefs about the disclosure of mental illness. Semi-structured, face to face interviews were conducted with parents (n= 26) regarding their thoughts about disclosure to their children about the mental illness of a parent. Participants included parents with mental illness, partners of parents with mental illness, ex-partners of parents with mental illness and step parents of children whose parent has mental illness. Participants ranged in age from 27 to 50 years old (mean age of 39 years). Interviews were audio taped and interview data was analysed using thematic analysis. Analysis suggested that disclosure about mental illness is a difficult process and rarely are parents able or willing to provide their children with information about all aspects of their illness.

Study two was an explorative study, utilising the Leventhal (1980) framework of illness understanding, which aimed to examine children's knowledge of their parent's illness. Children’s ideas about the disclosure process were also examined. Semi-structured, face to face interviews
were conducted with 40 children who had at least one parent with mental illness. Participants ranged in age from 7 to 17 years old (mean age of 11.9 years). Interviews were audio taped and subsequently analysed. Thematic analysis of the data suggested that children had varying degrees of understanding about their parent's mental illness and that this was not often associated with the age of the child. The data within the second study also highlighted that there are a number of children who would prefer not to know about their parent's illness.

In order to provide a comprehensive view of the disclosure of mental illness within a family context, this thesis briefly examined the family view of disclosure as well as familial beliefs about mental illness. Study three was a secondary analysis of selected findings from both studies one and two which aimed to compare three families' views about familial communication regarding mental illness. Individual family member's accounts of their beliefs about aspects of mental illness were examined and compared with other family members' beliefs. The congruence and incongruence of family accounts was highlighted.

This exploratory thesis provides a much needed insight into the experience of disclosure from both a parent and child perspective. It is also the first study to provide a structured examination of children’s beliefs about parental mental illness. There are a number of key clinical implications which are informed by the findings of this thesis. The assumptions which underpin the claim that all children should be educated about a parent’s mental illness need to be carefully considered. Parents have difficulty explaining aspects of mental illness to children and, importantly, some parents actively choose not to explain specific elements of mental illness to their children. Some children do want more information about their parent's mental illness, however others actively avoid talking about the illness or avoid seeking out further information. From a clinical perspective, people working with parents with mental illness or their children need to be mindful of the difficulties for both parents and children around the disclosure of mental illness to children.