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Experiences of adult children living with a mentally ill mother

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EXPERIENCES OF ADULT CHILDREN LIVING WITH A MENTALLY ILL MOTHER

by

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A research report submitted to the faculty of Health Sciences, University of the Witwatersrand, in partial fulfilment of the requirements for the degree of Master of Science in Nursing

Department of Nursing Education

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June 2016

DECLARATION

I, Nobuhle Princess Makaula hereby declare that this research report is a product of my own original work, unless otherwise stated, and that all sources that I have used or quoted have been indicated and acknowledged by means of complete and accurate referencing. I also declare that this research has not been previously published.

Signature: _____ Date: _____

N.P. Makaula

Student Number: 687892

DEDICATION

To my mother Florence, my son Ongama and my brothers Zakhe, Bongani, Linda and Ntsindiso.

ACKNOWLEDGEMENTS

I would like to thank my family for their love and continued support. Your words of encouragement kept me going during the difficult times.

To my supervisor, Annalie van den Heever, thank you for your patience with me. Your encouragement and support kept me motivated to finish this project.

I would also like to thank the research committee of the institution in which the study was conducted for allowing me to conduct the study.

Most importantly I would like to thank all the people who participated in this project by sharing their experiences. Without you this project would not have been a success.

ABSTRACT

Parental mental illness has been described as one of the major life events with negative effects that a person can experience. Mental illness affects roles and functioning among family members. The objective of the study is to explore and describe the experiences of adult children living with a mentally ill mother. This study followed a descriptive qualitative design with a purposive sampling method. The sample comprised of five adult children (n=5) living with mentally ill mothers, whose mothers are admitted at a Specialist Psychiatric Hospital using semi-structured interviews. Thematic content data analysis was used to analyse data.

Findings revealed that adult children of the mentally ill mothers experience various emotions about living with a mentally ill mother. Concerns regarding taking care of the mentally ill mother, time spent taking care of the mother and the effects the mother's mental illness has on relationships were the reported experiences.

It is recommended that the assessment of needs, identification of the resources, education on relapse management and provision of support groups be done by mental health care nurses to better the experiences of living with a mentally ill mother among the adult children.

CONTENTS

DECLARATION…….…... (i)

DEDICATION……..... (ii)

ACKNOWLEDGEMENTS…… (iii)

ABSTRACT…….....(iv)

TABLE OF CONTENTS……...(v)

LIST OF TABLES……..(x)

CHAPTER 1: INTRODUCTION AND OVERVIEW OF THE STUDY……10

1.1 INTRODUCTION……...1
1.2 BACKGROUND……..…… 1
1.3 PROBLEM STATEMENT……3
1.4 RESEARCH QUESTION……3
1.5 PURPOSE OF THE STUDY……...……3
1.6 OBJECTIVE……..…...4
1.7 RESEARCH METHOD……..……4
1.7.1 Design……..4
1.7.2 Population ……..4
1.7.3 Sample……..4
1.7.4 Inclusion criteria……....4
1.7.5 Sampling method……..5
1.7.6 Sampling size…….……5
1.7.7 Data collection……...5
1.7.8 Data analysis……..7
1.8 TRUSTWORTHINESS……7
1.8.1 Credibility……7
1.8.2 Transferability……7
1.8.3 Dependability……7
1.8.4 Confirmability…… 7

1.9 ETHICAL CONSIDERATIONS……..…….... .7
1.10 CLARIFICATION OF CONCEPTS…….. .9
1.11 CONCLUSION……..9

CHAPTER 2: LITERATURE REVIEW…….……....10

2.1 INTRODUCTION……..10
2.2 FAMILIES WITH MENTAL ILLNESS……...10
2.2.1 Emotional Burden……10
2.2.2 Financial Burden……...11
2.3 CHILDREN OF THE MENTALLY ILL…….. 11
2.3.1 Childhood……11
2.3.2 Adolescent…… 11
2.3.3 Adulthood……12
2.4 FAMILY SYSTEMS THEORY…… 13
2.5 ATTACHMENT THEORY …….. 14
2.6 CONCLUSION…….. 14

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY…… 15

3.1 INTRODUCTION…….. 15
3.2 RESEARCH PROBLEM……..15
3.3 PURPOSE AND OBJECTIVES OF THE STUDY…….. 15
3.4 DESIGN AND METHOD……..16
3.4.1 Design……..16
3.4.2 Method……16
3.4.3 Strengths of the qualitative method…… 17
3.4.4 Limitations of the qualitative method…… 17
3.4.5 Measures to ensure trustworthiness…….. 17
3.4.5.1.1 Credibility……..18
3.4.5.1.2 Transferability……..18
3.4.5.1.3 Dependability……...18
3.4.5.1.4 Confirmability…….. 18
3.5 METHODOLOGY…… 19

3.5.1 Population…….. 19
3.5.2 Sampling……. 19
3.5.3 Inclusion Criteria…….. 19
3.5.4 Exclusion Criteria……. 19
3.5.5 Sampling technique……. 20
3.5.6 Sampling size Data collection……...20
3.5.7 Data collection……...21
3.6 RESEARCH SETTING…… 21
3.7 SEMI STRUCTURED INTERVIEWS……..…….. 21
3.8 DATA COLLECTION PROCESS…….…22
3.9 MEASURES TO ENSURE TRUSTWORTHINESS…….....24
3.9.1 Credibility…… ……24
3.9.2 Transferability…… ……24
3.9.3 Dependability…… 24
3.9.4 Confirmability…….……...…24
3.10 ETHICAL CONSIDERATIONS……25
3.11 DATA ANALYSIS……..……26
3.12 SAFEGUARDING DATA……..... 26
3.13 CONCLUSION…….....26

CHAPTER 4: DISCUSSION OF THE FINDINGS……. 27

4.1 INTRODUCTION…….. 27
4.2 DESCRIPTION OF THE SAMPLE…… 27
4.3 DATA ANALYSIS……27
4.4 DISCUSSION OF THE INTERVIEW DATA……. 28

CHAPTER 5: DISCUSSION, LIMITATIONS AND RECOMMENDATIONS.……38

5.1 INTRODUCTION……..…..38
5.2 DISCUSSION OF FINDINGS…… 38
5.3 RECOMMENDATIONS……...…...41
5.3.1 Assessment of needs…….. 41
5.3.2 Identification of resources…..42

5.3.3 Education on relapse prevention…… 42
5.3.4 Support groups…… 42
5.3.5 Limitations of the study…….. 42
5.4 CONCLUSION…….. 42

REFERENCE LIST……43

APPENDIX A: INFORMATION SHEET……..45

APPENDIX B: CONSENT FORM FOR RECORDING THE INTERVIEWS……..47

APPENDIX C: CONSENT FORM FOR SEMI-STRUCTURED INTERVIEWS…….48

APPENDIX D: INTERVIEW SAMPLE……..…..49

APPENDIX E: CLEARANCE CERTIFICATE……..…….59

APPENDIX F: LETTER FROM THE INSTITUTION…… 60

LIST OF TABLES

Table 3.1: Data Analysis of the Interviews.

CHAPTER 1

1.0 INTRODUCTION AND OVERVIEW OF THE STUDY

1.1 Introduction

In chapter 1, the study is introduced; outlining its background and a summary of the methodology is explained.

1.2 Background

Parental mental illness has been described as one of the major negative life events that a person can experience. More severe is the major mental illnesses including Schizophrenia, Bipolar Mood Disorder, Generalized Anxiety Disorder and Major Depressive Disorder.

The children of the mentally ill parents represent a vulnerable group of the population as they are at a higher risk of developing mental illness than those who do not have mentally ill parents (Garley, Gallop, Johnston & Pipitone, 1997). This is because they are genetically predisposed to the mental illness. The unpredictable and inconsistent family environment due to the parent's mental illness also puts the children at risk of developing mental illness if they have a parent who is mentally ill.

The inconsistent and unpredictable behaviour of those living with mental illness is brought about by the alteration cognition that the mental illness causes. This alteration in cognition affects the functioning of the person and how they carry out their roles. This effect in roles may bring about undesirable effects in the family system.

The change in one person's functioning within the family unit is predictably followed by reciprocal changes in the functioning of other family members (Sadock & Sadock, 2007). This illustrates that as mental illness is known to affect a person's functioning, it is expected that one family member suffering from mental illness will affect the family as a unit.

The children of the mentally ill parents, while visiting their mothers who are admitted in a Specialist Psychiatric Hospital, have been observed to present with various feelings of distress related to their parents" mental illness. They are observed to

present with anxiety and fear due to the unpredictable nature of the parent's mental illness. They often worry about the safety of the mother and also the possibility of relapse. According to the World Health Organisation (2003), the family members are often the primary caregivers of people with mental disorder, and are expectedly the ones that have more burden of caring for the sufferers of mental illness. Saunders (2009), while studying the families of the mentally ill noted that the caregivers of persons with severe mental illness suffer from significant stresses, experience moderately high levels of burden and often receive inadequate assistance from the mental health care professionals.

The children of the mentally ill parents also report to be feeling neglected by the mental health care system. They report feeling the parents and their mental illness are the main focus during admission and their feelings and needs are often neglected during the parents' admission. They often report this in relation to the difficulties encountered while making means to visit the parent, which related to either monetary or time limitations. They also indirectly report feeling pressured by the mental health care providers to visit or collect parents for pass out visits at home, without the circumstances being adequately explored as observed in the written and verbal pass out feedback they give about the parents' visit.

The children of the mentally ill parents also report stress due to the financial burden that comes with having a mentally ill parents whose role of providing for the family is compromised. They report added financial stressors during admission where they need to visit the inpatient parent on a regular basis. They report that even though the financial burden is evident, they feel guilty if they do not make means beyond their financial burden to go and visit their parents during admission. World Health Organisation (2003) reports that the economic impacts of mental illness affect personal income, the ability of the ill persons to work, and the ability of their caregivers to work.

The mother is the primary caregiver that the child attaches to. Mother-child attachment is the essential medium of human interaction and has important consequences for later development and personality functioning (Sadock & Sadock, 2007). The presence of mental illness within the mother can negatively affect this attachment resulting negative consequences later in life. The mother often plays a

major role in rearing the child and therefore a healthy relationship is essential between the mother and the child.

The information available from the studies on the relationship between the mental illness of the mother and the child is retrospective data (Polkki,Ervast & Huupponen 2005). There is a lack of information on the emotional experiences of living with a mentally ill mother. The focus is primarily on the mentally ill person. The extent of the burden of mental disorders on family members is difficult to assess, and quantity is consequently ignored (WHO, 2003). Hence the purpose of this study is to explore and describe the experiences of adult children who had been living with a mentally ill mother; the influence that the mother's mental illness has had on the adult child. For the purposes of this study, mother refers to any female who is the primary caregiver. The adult child refers any of the following: male, female, biological, adopted or step child.

1.3 Problem Statement

There is a lack of knowledge on the experiences of adult children living with a mentally ill mother. The focus has primarily been on the mentally ill person while the experiences of those living with the mentally ill person are often not taken into account, therefore little or no support seems to be given to them.

As a psychiatric nurse working in a Specialist Psychiatric Hospital, I have observed family members' anxiety around their mothers' mental illness and commonly observed amongst the adult children who have their mothers admitted for mental illness. These adult children often verbalise anxiety and confusion due to the lack of knowledge about the mother's mental illness, and sometimes report being overwhelmed by the situation of having a mentally ill mother.

1.4 Research Question

To explore the research question of how adult children experience living with a mentally ill mother, the following questions were asked:

What are the experiences of living with a mentally ill mother?

How has living with a mentally ill mother influenced the lives of their adult children?

1.5 Purpose of the Study

The purpose of the study is to explore and describe the experiences of adult children living with a mentally ill mother and how their mother's illness has influenced their lives.

1.6 Objectives

The objectives of the study are:

To explore the experiences of adult children living with a mentally ill mother

To describe the influence that living with a mentally ill mother has on the adult child

1.7 Research Method

1.7.1 Design

Descriptive Qualitative Design

1.7.2 Population

The population for this study was comprised of adult children of mentally ill mothers who were visiting their mothers while they were admitted at a Specialist Psychiatric Hospital.

1.7.3 Sample

The sample for the study consisted of the adult children of mentally ill mothers. The participants were those who lived with the mother for a minimum of a year during their teenage years before they were 18 years old. Participants were those who were able to reflect on and describe their experiences.

1.7.4 Inclusion Criteria

Participants who are living with or having lived with a mentally-ill mother for a minimum of a year and being exposed to three or more episodes of their mother's illness phase.

The mother had suffered from a major mental illness i.e. Schizophrenia, Bipolar Mood Disorder, Major Depressive Disorder or Generalised Anxiety.

Participants (adult child) were not displaying psychotic features or evidence of experiencing a current episode of mental disorder as this may affect the person's behaviour and functioning and may also affect the way they articulate and reflect on their experiences.

1.7.5 Sampling Method

A purposive sampling method was used. The participants that would most benefit from the study were identified (Polit & Beck 2012). As the approach to be used with the study was flexible and emergent, the information obtained from the initial participants determined the subsequent selection of more participants. The aim was to include a variety of participants according to factors such as gender and different backgrounds as participants with these different attributes are likely to have different experiences.

1.7.6 Sampling Size

Data saturation determined the size of the sample. Data saturation was reached when no new information or themes were being obtained from the participants.

1.7.7 Data Collection

Semi-structured interviews to gather data were used. Conversational exchange between the interviewer and the participant was the main source of information. A written topic guide was used that included broad questions such as:

"What has been your experience of living with a mentally ill mother?"

"How has living with a mentally ill mother influenced your life?"

Probing was also used with the aim of getting more information from the data provided by the participants. This was done to explore issues brought up in greater depth to get more information about participants' needs and perceived impact of living with a mentally-ill mother.

The interviews were audio taped and later transcribed in preparation for data analysis. Potential participants were approached during the time they visit their mothers. A suitable time for the interview was arranged between the participants and

the researcher. The interviews were conducted in a private room within the hospital, during a time suitable for both the researcher and the participant.

1.7.8 Data Analysis

Thematic Content Data Analysis was used, which aims at searching for broad categories or themes (Polit & Beck, 2012). This included using the similarity principle and contrast principle; where units of information with similar content, symbols or meaning are looked for, and an effort is made to find the distinction from the emerging themes. A distinction between the ideas that apply to all or most participants and ideas unique to certain participants was also made. The patterns in which the themes arise were also taken into consideration (Polit & Beck, 2012). This includes looking at the context from which the themes arise, certain periods and certain people in which these themes arise and the relationship between these themes of information.

1.8 Trustworthiness

Lincoln and Guba's Framework for establishing trustworthiness was used, which is suggested for a study that is explorative and descriptive in nature (Polit & Beck, 2012).Four criteria must be met in order to achieve trustworthiness in a study (Polit & Beck, 2012).

1.8.1 Credibility

This is achieved by ensuring confidence in the truth and interpretations of the data (Polit & Beck, 2012). This is done to enhance believability of the findings, ensuring congruency of results with reality. This was achieved by using research methods that are well establish for this kind of a study, such as semi-structured interviews to collect data, and audio taping the interviews. Frequent debriefing with the supervisor ensured that correct methods are used and the data is collected in a way that is relevant for this kind of a study. Thick descriptions of the experiences shared by the participants also helped in ensuring the credibility of the study.

1.8.2 Transferability

Transferability is concerned with ensuring that the findings of the study can be transferred to or be applicable in other similar settings (Polit & Beck, 2012). This was achieved by including as much detail as relevant about the contextual information of the field of the study and setting in which the study takes place.

1.8.3 Dependability

Dependability is concerned with the stability of data over time and conditions (Polit & Beck, 2012) and answers the question of whether the findings would be applicable if the study was repeated with similar participants in a similar context. The researcher ensured stability of data by reporting in detail the process of the study, the design and data collection process.

1.8.4 Confirmability

Confirmability is concerned with establishing that data represents the information that the participants provided and that the interpretations are not influenced by the researcher's own beliefs and attitudes (Polit & Beck, 2012). This was ensured by admission of the researcher's beliefs and assumptions through constant reflection throughout the study. The findings were taken back to the participants for confirmation that they represent the experiences they shared with researcher. This was done by contacting two participants after transcription of the data from the interviews, and clarifying with them whether they agree with the data transcribed. This was done before the data was analysed.

1.9 Ethical Considerations

Permission was obtained from the Post Graduate assessors' committee to conduct the study. Permission to conduct the study was obtained from the University of the Witwatersrand's Research and Ethics Committee before the study could be carried out. (Ethics No: M130735, Appendix E)

Permission will also be obtained from the Research and Education Committee of the Specialist Hospital in which the study was conducted (Appendix F).

The information sheet was given to the participants. The information sheet explained the nature of the study and enabled them to make an informed decision about participating in the study (Appendix A). This was done to ensure that the participants' right to full disclosure is ensured.

A signed informed consent was obtained from the participant before they could take part in the study. Individual informed consent was also obtained for the research tools to be used in the study; a separate informed consent was obtained for conducting semi-structured interviews (Appendix C) and another one for recording the interviews (Appendix B).

To ensure participants' right to privacy, the information obtained from the interview was only made available to the researcher and the supervisor and was only used for research purposes. Confidentiality was maintained throughout the study.

No identifying information was used in reporting the findings to maintain participants' right to anonymity.

The information acquired in the study may be sensitive to some participants and may heighten emotional awareness. The impact of these experiences could pose a challenge for children to deal with during the course of the study. To ensure non maleficence, participants who might have experienced heightened emotional awareness would have been referred for counselling. A unit manager and two supervisors for the study, who are all advanced psychiatric practitioners, had agreed to assist with counselling.

Participation in the study was voluntary to ensure participants' right to self-determination. It was also explained to them that they have a right to ask questions anytime they need to and refuse to give information they are not comfortable with. The participants also had a right to withdraw from participating in the study at any time, with no consequences or detriment to the care of their mother in any way.

1.10 Clarification of the concepts

Experiences

Experience, according to the Oxford Dictionary, is a personal observation or knowledge. For the purposes of this study, the experiences will mean the adult child's feelings, needs and expectations regarding their mother's mental illness.

Influence

Influence is defined by the Oxford Dictionary as the capacity to have an effect or impact on the character, development or behaviour of someone or something.

Mother

According to the Oxford Dictionary, mother means a female parent. For purposes of this study, mother refers to any female who is the primary caregiver and the one bringing up the child.

Adult Child

In this study, an adult child will mean a person who is 18byears or older, who was brought up by a mentally ill mother.

Mentally Ill

According to the Oxford Dictionary, mental illness is defined as a condition that causes a serious disorder in a person's behaviour and thinking. The mothers whose adult children will be interviewed will be suffering from one of the major mental illnesses including major depressive disorder, schizophrenia, bipolar mood disorder and generalised anxiety disorder.

1.11 Conclusion

In chapter 1, the background to the study and a summary of the methodology was explained. Chapter 2 is an in-depth discussion of the literature with regards to families living with mental illness.

CHAPTER 2

2.0 LITERATURE REVIEW

2.1 Introduction

Family members of the mentally ill persons are often the primary caregivers to their mentally ill family members. The burden that results from caring for the mentally persons affects individuals in various aspects of their lives. This chapter reviews the families living with mentally ill individuals, focusing on the complexities and emotional influences as well as the theories related to mental illness and family interaction.

2.2 Families living with mental illness

Families living with a mentally ill individual are affected in different aspects. The mental illness affects the person's behaviour and functioning, and as a result, the roles of the mentally ill person within the family are affected. This in turn results in other family members having to adjust these roles according to needs of the family in order for the family to be functional. This effect in roles often results in burden of caring for the mentally ill person within the family.

Mental illness alters a person's behaviour as it affects the person's cognition and perceptions (Sadock & Sadock, 2007). This alteration affects the person's functioning and how they carry out their roles. Having a mother that suffers from a severe mental illness affects the normal relationship between the mother and the child (Polkki, Huupponen & Ervast, 2005). It affects the mother's role of rearing the child.

2.2.1 Emotional burden

O'Connell (2008) observed that living with a mother that is mentally ill affects the social life of the child. In the study that O'Connell conducted it was found that the children of the mentally ill mothers assumed the role of the mother as the mother was unable to fulfil her role due to mental illness. Social life was also found to be affected due to the stigma associated with mental illness where the children felt alienated from the society (Fjone, Ytterhus & Almvit, 2009).

Rose, Mallison and Gerson (2006) noted that the children of the mentally ill constitute a group that is neglected by the mental health care providers. The focus is primarily on the mentally ill person and not on those that might be affected by the mental illness. In a study by Duncan and Browning (2008), the children of the mentally ill parents reported to finding the mental health care providers not being helpful, and also found the health care providers to be harmful by blaming them for their parents' mental illness.

2.2.2 Financial burden

In a study done by Polkki et al (2005) it was found that the parental mental illness can bring about financial constraints in the family. The mentally ill parent is sometimes unable to work and take care of the children while the social welfare department often has to intervene. Children who experienced verbal and physical abuse from mentally ill parents were found to be affected emotionally.

2.3 Children of the mentally ill

2.3.1 Childhood

The children of the mentally are considered a population that is at risk of developing psychiatric condition due to the environment they grow up in and also the genetic predisposition to the mental illness. Longitudinal studies have shown that children of the affectively ill parents are at a greater risk of developing psychiatric disorders than children from homes with non-ill parents (Beardselee, Versage & Giadstone, 1998).

Mattejat and Remschmidt (2008) noted that there are increased reports of child abuse and even death among the children of the mentally ill parents. They also noted increased reports of adverse events among children brought up by mentally ill parents.

2.3.2 Adolescence

The children of the mentally ill parents experience negative effects from being raised by the mentally ill parent. This is due to the unpredictable nature of the parent's mental illness the erratic parenting they receive causes them to live in fear (Tronsend, 2011). In the same study done by Tronsend (2011) on 15 to 18 year old

Norwegian adolescents, the participants reported loneliness, loss and sorrow due to their upbringing by the mentally ill parent.

A lack of information about the parent's condition has also been reported as a factor contributing to anxiety and uncertainty reported among the adolescent children of the mentally ill parents (Tronscend, 2011). This made them feel a heavy burden as they would not know what to expect in the parents behaviour.

According to a study done by Helmut and Fritz (2005:415) on children who were 12 to 18 years old, children of a mentally ill person are at a higher risk of developing mental illness due to the impairment of mother-child interactions that is brought about by the mother's mental illness. Another factor that was found to contribute to the vulnerability of the children of the mentally ill mother to mental illness was the genetic influence as mental illness is also hereditary (Pretis & Dimova, 2008).

2.3.3 Adulthood

Growing up with a mentally ill parent can have detrimental effects in a child's life. These effects are sometimes carried through the life of the child with after effect manifesting even in adulthood. These negative effects are brought about the abuse and neglect that is often reported in the parenting of the mentally ill individuals. On a study done by O'Conell (2008) among adults who were raised by the mentally ill mothers, participants reported to have had disruptive childhoods, having to move from one place to another in a short period of time. The experiences were reported to be painful.

On a prospective study done by Horwitz, Widom, McLaughlin and White (2001) it was found that men and women who were abused and neglected as children have more dysthymia and antisocial personality disorders as adults. In the same study it was found that after controlling the stressful life events, childhood neglect and abuse had little direct impact on any lifetime mental health outcome.

As individuals are different and react differently to certain stimuli, it is expected that people who were raised by mentally ill parents will have different outcomes and different experiences of being raised by a mentally ill mother. This is an observation that was made by Petris and Dimova (2008). They reported that individuals have different resilient factors that protect them against having adverse effects from living

with a mentally ill mother. These resilient are reported to minimise the adverse effects. O'Conell (2008) also reported that although negative experiences were reported amongst the participants, most of them turned out to be well functioning as a result of their own initiative.

In some studies it has been noted that although living with a mentally ill mother has some adverse effects on a person, there are measures that may be taken to minimise the effect on adults who were raised by the mentally ill mothers. Mattejat and Remschmidt (2008) suggested that fostering an attachment with a healthy adult or even a professional in the field of mental health can assist in minimising the effect in adulthood. It is also suggested that giving information to the children of the mentally ill about their parents' condition gives clarity and predictability to the child helping them to cope with the situation.

2.4 Family Systems Theory

The family systems theory addresses the emotional forces that shape the functioning of the nuclear and extended family (Papero, 1983). The family systems theory assists in understanding families and how they function as a singular entity.

Bowen's family systems theory states that a change in one person's functioning within a family unit is predictably followed by reciprocal changes in the functioning of the other family members (Papero, 1983). This illustrates that as mental illness is known to affect a person's functioning (Sadock & Sadock, 2007), it is expected that one family member suffering from mental illness will affect the whole family.

The children of the mentally ill being part of a family are expected to be affected by the mother's mental illness, according to the family systems theory. This affected is also expected as the presence of mental illness affects roles and functioning. In parents it is expected to affect the parenting and thus affecting the child.

2.5 Attachment Theory

Attachment theory is an attempt to understand the disturbed functioning of the individuals who had experienced traumatic losses or early separation, a theory of normal development that offers explanations for some types of atypical development (Hillis, Anda, Felitti, Nordenberg & Marchbanks, 2001).

According to Attachment theory (Sadock & Sadock, 2007), the mother is the primary caregiver that the child attaches to. Mother-child attachment is the essential medium of human interaction and has important consequences for later development and personality functioning (Cassidy, 2002). The mother often plays a major role in rearing the child and therefore a healthy relationship is essential between the mother and the child.

The predictable outcome of the infant's attachment behaviour is attainment of proximity of a trusted person (Crittenden & Ainsworth, 1989). As it was noted earlier that the children of the mentally ill mothers often experience abuse and neglect, the trust essential for the secure attachment is compromised in the mother-child relationship where mental illness exists. The infant's patterns of attachment are closely related to the behaviour of the attachment figure in question (Crittenden & Ainsworth, 1989).

The children of the mentally ill parents often form anxious or insecure attachments. The anxious or insecure attachment is common among children who experience family maltreatment (Hillis et al, 2001). The kind of attachment formed by infants during early development can be displayed in adulthood. Among individuals with a history of adverse childhood experiences, risky sexual behaviour may represent their attempt to achieve and maintain interpersonal connections (Hillis et al, 2001).

The information available from the studies on the relationship between the mental illness of the mother and the child is retrospective data (Polkki et al, 2005). There is a lack of current information of the experiences of adult children living with a mentally ill mother.

2.6 Conclusion

In this chapter, the literature about the families living with mental illness was reviewed. In the next chapter, the research design and methodology will be discussed.

CHAPTER 3

3.0 RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

The literature, discussed in chapter 2 highlighted the complexities and emotional influences on families living with mental illness. In chapter 3 the research design and methodology of the study will be discussed in greater detail.

3.2 Research problem

There is a lack of knowledge on the experiences of adult children living with a mentally ill mother. The focus has primarily been on the mentally ill person while the experiences of those living with the mentally ill person are often not taken into account, therefore little or no support seems to be given to them.

As a psychiatric nurse working in a Specialist Psychiatric Hospital, I have observed family members' anxiety around their mothers' mental illness and commonly observed amongst the adult children who have their mothers admitted for mental illness. These adult children often verbalise anxiety and confusion due to the lack of knowledge about the mother's mental illness, and sometimes report being overwhelmed by the situation of having a mentally ill mother.

3.3 Purpose and objectives of the study

- The purpose of the study is to explore and describe the experiences of adult children living with a mentally ill mother and how their mother's illness has influenced their lives. From the study, recommendations will be made as to how the health care professionals providing mental health care to the mothers and assist the adult children in coping with their mothers illness according to the experiences they elicit in the study. The following objectives were set.
- To explore the experiences of living with a mentally ill mother.
- To describe the influence that living with a mentally ill mother had on the adult child.

3.4 Design and method

3.4.1 Design:

A qualitative, descriptive design was used. A research design serves as a guide for the study as it guides the planning and the implementation of the study (Burns & Grove, 2005). The suitable design for this study would be a qualitative descriptive design as it seeks to explore and describe the experiences of adult children living with a mentally ill mother. Qualitative research is a systematic, subjective approach used to describe life experiences and give them meaning (Burns & Grove, 2005). The experiences of adult children living with a mentally ill mother will be explored and described. Qualitative research aims to address questions concerned with developing an understanding of the meaning and experience dimensions of humans' lives and social worlds (Burns and Grove, 2005).

The aim of the descriptive study is to describe phenomena without providing the causal explanations of the phenomenon (Terre-Blanche, Durrheim & Painter, 2007). The data collected is not manipulated, i.e. the environment is not changed. The information is gathered from a representative sample of the population. This study is descriptive as it seeks to obtain descriptions of the experiences of adult children living with a mentally ill mother.

3.4.2 Method

The research method will serve as a guide for data collection (Terre-Blanche et al, 2007). A qualitative and a descriptive design will be used for this study to explore and describe the experiences of adult children living with a mentally ill mother. In this chapter, the research method will be explained in detail as to what it entails and the strengths and the weaknesses of the chosen research method will be looked at. The qualitative research method will be used.

The qualitative method is used to gain an understanding of underlying reasons, opinions, and motivations. It provides insights into the problem. Qualitative Research is also used to uncover trends in thought and opinions, and look deeper into the problem. It uses research techniques that seek insight through verbal data rather than scaled data. The methods used are interactive and humanistic with active participation by the participants and sensitivity towards the participants.

3.4.3 Strength of the Qualitative Method

When using the qualitative method, data is based on participants' own categories of meaning and it is useful for describing complex phenomena. It provides understanding and description of people's personal experiences of phenomena. It enables the researcher to study dynamic processes as it produces more in-depth, comprehensive information, seeking a wide understanding of the entire situation.

3.4.4 Limitations of the Qualitative Method

The subjective nature of the data used may lead to challenges in establishing reliability and validity of the information. The results may be influenced by the researcher's personal biases and idiosyncrasies which may be difficult to detect or prevent. The findings may not be generalised to other contexts due to the qualitative method's in-depth and comprehensive data gathering approaches that limit generalisation to other contexts.

Data analysis is the systematic organisation and synthesis of research data (Polit & Beck, 2012). Data analysis has to be assumed by the researcher by first removing all preconceived expectations about the phenomenon by a process called bracketing (Burns & Grove, 2005). Thematic content data analysis was the method used to analyse data. Themes were extracted from the transcripts. A theme is an entity that brings meaning and identity to a current experience and its variant manifestations (Polit& Beck, 2012). A theme captures and unifies the nature the nature or basis of the experience into a meaningful whole. The information was divided into themes. Under the themes further emerged the sub themes which were different categories of information further explaining the themes. Verbatim quotations were selected which evidence the different sub themes.

3.4.5 Measures to ensure trustworthiness

Lincoln and Guba's Framework for establishing trustworthiness will be used, which is suggested for a study that is explorative and descriptive in nature (Polit & Beck, 2012).Four criteria must be met in order to achieve trustworthiness in a study (Polit & Beck, 2012).

3.4.5.1 Credibility

This is achieved by ensuring confidence in the truth and interpretations of the data (Polit & Beck, 2012). This is done to enhance believability of the findings, ensuring

congruency of results with reality. This was achieved by using research methods that are well establish for this kind of a study, such as semi-structured interviews to collect data, and audio taping the interviews. Frequent debriefing with the supervisor ensured that correct methods were used and the data was collected in a way that is relevant for this kind of a study. Thick descriptions of the experiences shared by the participants also helped in ensuring the credibility of the study.

3.4.5.2 Transferability

Transferability is concerned with ensuring that the findings of the study can be transferred to or be applicable in other similar settings (Polit& Beck, 2012). This was achieved by including as much detail as relevant about the contextual information of the field of the study and setting in which the study took place.

3.4.5.3 Dependability

Dependability is concerned with the stability of data over time and conditions (Polit & Beck, 2012) and answers the question of whether the findings would be applicable if the study was repeated with similar participants in a similar context. The researcher ensured stability of data by reporting in detail the process of the study, the design and data collection process.

3.4.5.4 Confirmability

Confirmability is concerned with establishing that data represents the information that the participants provided and that the interpretations are not influenced by the researcher's own beliefs and attitudes (Polit & Beck, 2012). This was ensured by admission of the researcher's beliefs and assumptions through constant reflection throughout the study. The findings were taken back to the participants for confirmation that they represent the experiences they shared with researcher. This was done by contacting two participants after transcription of the data from the interviews, and clarifying with them whether they agree with the data transcribed. This was done before the data was analysed.

3.5 Methodology

3.5.1 Population

The population is the target group that meets the inclusion criteria of the sample for the study (Burns & Grove, 2005). The target population was the adult children of mentally ill mothers who were admitted at a specialist psychiatric hospital who are visiting their mothers.

3.5.2 Sampling

A sample is a subset of a population comprising those selected to participate in a study (Polit & Beck, 2012). Adult children who were visiting their mothers in hospital were invited to participate in the study.

3.5.3 Inclusion Criteria

The inclusion criterion is determined by certain characteristics identified by the researcher that must be possessed by each participant in order to be included in the study (Burns & Grove, 2005). Participants were those who had lived with a mentally-ill mother at any time of their lives and being exposed to three or more episodes of their mother's illness phase. The mother had suffered from a major mental illness i.e. Schizophrenia, Bipolar Mood Disorder, Major Depressive Disorder or Generalised Anxiety. Participants chosen to participate in the study were those who are proficient in English.

3.5.4 Exclusion Criteria

The adult children who were not able to communicate in English were excluded. The quality of information obtained from each participant is the justification of the qualitative research paradigm and this quality can only be elucidated by the language and the metaphors used by the participant and understood by the researcher (Terre-Blanche et al, 2007). English was used as it the language best understood by the researcher. Participants (adult child) who were displaying psychotic features or evidence of experiencing a current episode of mental disorder were excluded as this may affect the person's behaviour and functioning and may also affect the way they articulate and reflect on their experiences.

3.5.5 Sampling Technique

Sampling is the process of selecting a portion of the population to represent the entire population (Polit & Beck, 2012). The sampling is conducted in different ways. For this study, a purposive sampling method was used. They were approached while visited their mothers who were admitted at a specialist psychiatric hospital.

3.5.6 Sample Size

Data was collected from adult children of mentally ill mothers until saturation was reached. Saturation is the collection of qualitative data to the point where a sense of closure is attained because new data yield redundant information (Polit & Beck, 2012). Polit and Beck (2012) also state that if participants are good informants who are able to reflect on their experiences and communicate effectively, saturation can be reached with a relatively small sample.

Permission to conduct the study was obtained from the University of the Witwatersrand's Research and Ethics Committee before the study can be carried out. Permission was also obtained from the Research and Education Committee of the Specialist Hospital in which the study will be conducted.

The information sheet was given to the participants which explained the nature of the study and enabled them to make an informed decision about participating in the study. This was done to ensure that the participants' right to full disclosure is ensured. A signed informed consent was obtained from the participants before they could take part in the study. Individual informed consent was obtained for the research tools to be used in the study; a separate informed consent was obtained for conducting semi-structured interviews and another one for recording the interviews.

To ensure participants' right to privacy, the information obtained from the interview was only available to the researcher and the supervisors and was used for research purposes. Confidentiality was maintained throughout the study. No identifying information was used in reporting the findings to maintain participants' right to anonymity.

The information acquired in the study may be sensitive to some participants and may heighten emotional awareness. The impact of these experiences may pose a challenge for children to deal with during the course of the study. To ensure non

maleficence, participants who might have experienced heightened emotional awareness would have been referred for counselling. A unit manager and two supervisors for the study, who are all advanced psychiatric practitioners, had agreed to assist with counselling.

Participation in the study was voluntary to ensure participants' right to self-determination. It was also explained to them that they have a right to ask questions anytime they need to and refuse to give information they are not comfortable with. The participants also had a right to withdraw from participating in the study at any time, with no consequences or detriment to the care of their mother in any way.

3.5.7 Data collection

The purpose of a research technique is to use a logical approach to obtain information about a specific subject.

3.6 Research Setting

Permission from the specialist psychiatric hospital research committee was obtained to conduct the study. The interviews were conducted in a biochemical ward within the hospital and permission was obtained from the unit manager to use her office space to conduct the interviews. The office provided adequate privacy for the interviews to be conducted. The participants were approached while visiting their mothers in the hospital. After consent to participate in the study was obtained, an appointment for the interview was set at a time convenient for both the participant and the researcher.

3.7 Semi-Structured Interviews

An interview is a data collection method in which an interviewer asks questions of a respondent (Polit & Beck, 2012). Semi-structured interviews to gather data from the adult children living with a mentally ill mother were used. Conversational exchange between the interviewer and the participant was the main source of information. A written topic guide will be was used that included broad questions "What has been your experience of living with a mentally ill mother?" and "How has living with a mentally ill mother influenced your life?"

The interviews were conducted in a private room within the hospital to ensure confidentiality. Participants communicated in English. The interviews were audio

taped with the permission of the participants and later transcribed for analysis purposes.

The therapeutic communication skills were used such as reflecting, empathy, probing and clarifying during the interviews. Non-verbal communication of the participants was observed during the interview and recorded in the field notes.

Reflecting

The participants were listened to actively to get verbal and non-verbal messages and the feelings that were not explicitly communicated were stated back to them. This helped to better understand the meaning of what is being said.

Empathy

Empathy is a feeling of another's true emotions to be able to relate to the person by sensing true feelings that run deeper than those portrayed on the surface.

Probing

Probing is a communication skill used to elicit more from the information provided by the participant. Probing was also be used with the aim of getting more information from the data provided by the participants. This was done to explore issues brought up in greater depth to get more information about participants' needs and perceived impact of living with a mentally-ill mother.

Clarifying

Clarifying helps to seek mutual understanding between the researcher and the respondent and to explain what is vague. It helps the researcher to validate verbal and non-verbal information being communicated.

3.8 Data Collection Process

Data collection is the means of gathering information needed to address the research problem (Polit & Beck, 2012). In this study, information was collected with the use of semi-structured interviews with a written topic guide with broad questions.

A purposive sampling method was used in selecting the participants for the study. It is a conscious selection of the participants (Burns & Grove, 2005). The participants that would most benefit the study were selected (Polit & Beck, 2012). This was done

according to the inclusion criteria of this study. Participants who are able to communicate in English were selected.

The semi-structured individual interviews were used to explore the experiences of adult children living with a mentally ill mother. The participants understood and were able to talk about the two following broad questions that were asked during the interview:

“What has been your experience of living with a mentally ill mother?” and

“How has living with a mentally ill mother influenced your life?”

The interviews were conducted in a unit manager’s offices. This ensured privacy while conducting the interview. The interviews varied in length from 30 to 50 minutes. The interviews were audio taped with the consent of the research participants. The therapeutic communication skills were used during the interview such as probing, reflecting, clarifying to encourage participants to elaborate on feelings. The audio taped interviews were transcribed verbatim after the data was collected. Data saturation was reached at five participants. The data was analysed by the researcher. The researcher read the transcribed interviews several times to extract common themes and categories. One transcribed interview is attached at the end of the report.

Data analysis is the systematic organisation and synthesis of research data (Polit & Beck, 2012). Data analysis has to be assumed by the researcher by first removing all preconceived expectations about the phenomenon by a process called bracketing (Burns& Grove, 2005). Thematic content data analysis was the method used to analyse data. Themes were extracted from the transcripts. A theme is an entity that brings meaning and identity to a current experience and its variant manifestations (Polit & Beck, 2012). A theme captures and unifies the nature the nature or basis of the experience into a meaningful whole. The information was divided into themes. Under the themes further emerged the sub themes which were different categories of information further explaining the themes. Verbatim quotations were selected which evidence the different sub themes.

3.9 Measures to ensure trustworthiness

Lincoln and Guba's Framework for establishing trustworthiness will be used, which is suggested for a study that is explorative and descriptive in nature (Polit & Beck, 2012).Four criteria must be met in order to achieve trustworthiness in a study (Polit & Beck, 2012).

3.9.1 Credibility

This is achieved by ensuring confidence in the truth and interpretations of the data (Polit & Beck, 2012). This is done to enhance believability of the findings, ensuring congruency of results with reality. This was achieved by using research methods that are well establish for this kind of a study, such as semi-structured interviews to collect data, and audio taping the interviews. Frequent debriefing with the supervisor ensured that correct methods were used and the data was collected in a way that is relevant for this kind of a study. Thick descriptions of the experiences shared by the participants also helped in ensuring the credibility of the study.

3.9.2 Transferability

Transferability is concerned with ensuring that the findings of the study can be transferred to or be applicable in other similar settings (Polit & Beck, 2012). This was achieved by including as much detail as relevant about the contextual information of the field of the study and setting in which the study took place.

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Dependability is concerned with the stability of data over time and conditions (Polit & Beck, 2012) and answers the question of whether the findings would be applicable if the study was repeated with similar participants in a similar context. The researcher ensured stability of data by reporting in detail the process of the study, the design and data collection process.

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Confirmability is concerned with establishing that data represents the information that the participants provided and that the interpretations are not influenced by the researcher's own beliefs and attitudes (Polit & Beck, 2012). This was ensured by admission of the researcher's beliefs and assumptions through constant reflection throughout the study. The findings were taken back to the participants for confirmation that they represent the experiences they shared with researcher. This

was done by contacting two participants after transcription of the data from the interviews, and clarifying with them whether they agree with the data transcribed. This was done before the data was analysed.

3.10 Ethical Considerations

Permission to conduct the study was obtained from the University of the Witwatersrand's Research and Ethics Committee before the study can be carried out. Permission was also obtained from the Research and Education Committee of the Specialist Hospital in which the study will be conducted.

The information sheet was given to the participants which explained the nature of the study and enabled them to make an informed decision about participating in the study. This was done to ensure that the participants' right to full disclosure is ensured. A signed informed consent was obtained from the participants before they could take part in the study. Individual informed consent was obtained for the research tools to be used in the study; a separate informed consent was obtained for conducting semi-structured interviews and another one for recording the interviews.

To ensure participants' right to privacy, the information obtained from the interview was only available to the researcher and the supervisors and was used for research purposes. Confidentiality was maintained throughout the study. No identifying information was used in reporting the findings to maintain participants' right to anonymity.

The information acquired in the study may be sensitive to some participants and may heighten emotional awareness. The impact of these experiences may pose a challenge for children to deal with during the course of the study. To ensure non maleficence, participants who might have experienced heightened emotional awareness would have been referred for counselling. A unit manager and two supervisors for the study, who are all advanced psychiatric practitioners, had agreed to assist with counselling.

Participation in the study was voluntary to ensure participants' right to self-determination. It was also explained to them that they have a right to ask questions anytime they need to and refuse to give information they are not comfortable with.

The participants also had a right to withdraw from participating in the study at any time, with no consequences or detriment to the care of their mother in any way.

3.11 Data Analysis

Data analysis is the systematic organisation and synthesis of research data (Polit & Beck, 2012). Data analysis has to be assumed by the researcher by first removing all preconceived expectations about the phenomenon by a process called bracketing (Burns & Grove, 2005). Thematic content data analysis was the method used to analyse data. Themes were extracted from the transcripts. A theme is an entity that brings meaning and identity to a current experience and its variant manifestations (Polit & Beck, 2012). A theme captures and unifies the nature the nature or basis of the experience into a meaningful whole. The information was divided into themes. Under the themes further emerged the sub themes which were different categories of information further explaining the themes. Verbatim quotations were selected which evidence the different sub themes.

3.12 Safeguarding Data

Original copies of the transcriptions were kept in a safe place while extra copies were used during data analysis. This was done to avoid complete loss of information in case of an adverse event. Once the interview is transcribed, the transcript takes an independent reality and becomes the researcher's raw data. A file was made for each participant audiotaped interview, field notes and transcription. Labels were used to identify data to ensure easier access to information for the researcher.

3.13 Conclusion

In this chapter, the research design and the research methodology were discussed. In the next chapter, the findings of the research will be discussed.

CHAPTER 4

4.0 DISCUSSION OF THE FINDINGS

4.1 Introduction

The research design and research methods followed in this study were discussed in chapter 3. In this chapter the interpretation of data and literature control will be discussed. Thick descriptions of the characteristics, processes, transactions and

contexts that constitute the experience of living with a mentally ill mother will be provided.

Qualitative research involves ongoing analysis of the data to formulate subsequent strategies and to determine when data collection is done (Polit & Beck, 2012). The data collection and analysis took place concurrently until saturation was reached. The audio taped interviews were listened to several times while comparing them with the transcriptions. The experiences expressed by the participants were grouped into themes.

4.2 Description of the Sample

The sample in the study comprised of five participants. All participants were adult children of mentally ill mothers admitted at a specialist psychiatric hospital, ranging from age 19 years old to 38years old. Two of the participants were females and three of the participants were males. Two participants were white, two were black Africans and one was of Indian descent. All of the participants were employed. One participant was single, one participant was married and three of the participants were in a relationship.

4.3 Data Analysis

In qualitative research data is carefully and deliberately scrutinised, often reading data over and over in search of meaning and understanding (Polit & Beck, 2012). Themes that are representative of the experiences of living with a mentally ill mother were extracted by underlining words from the verbatim transcriptions. Main themes were identified and subthemes were developed as the analysis proceeded. The main themes identified were:

- Taking care of the mother
- Time spent in taking care of the mother
- Effect on relationships
- Emotional Impact

Thematic Content Data Analysis was used to analyse data. The themes and sub-themes are explained in table 4.1

Table 3.1 Data Analysis of Interviews

	Themes	**Sub themes**
1.	Taking care of the mother	A decline in functioning of the mother that is brought about by suffering from a mental illness increases the need to care for the mother due to: • *Loss of independence and poor judgement* Adult children felt responsible for ensuring the mother's daily basic needs are met in terms of: • *safety; food; medicine* Adult children felt the need adequately take care of the mother to ensure the prevention of Relapse Adult children also felt the obligation to take care of the mother because of: • *Guilt and perceived expectations*
2.	Time spent in caring for the mother	A lot of time is invested in taking care of the mentally mother by the adult children due to: • *Lack of support or not asking for help* • *The amount of time* invested in caring for the mother results in less personal time available for the adult children.
3.	Effect on Relationships	The presence of mental illness of the mother results in an effect on the relationships of: • *The mother and her friends and relatives* • *The mother and the child* • *The adult child and friends* • *The adult child and the father*
4.	Emotional Impact	Various emotions arise from being an adult child living with a mentally ill mother such as: • *fear; anger; hopelessness; irritation; guilt; embarrassment; sadness; frustration; worry; stress*

4.4 Discussion of the interview data

Theme 1: Taking care of the mother.

Loss of independence

The participants of the study indicated that a decline in functioning of the mother that is brought about by suffering from a mental illness increases the need to care for the mother. The decline in functioning results in the mother's independence being affected to a great extent. The adult children then feel the need to step in and assist their mothers in daily living activities. This is evident in the following quote:

"So you know in all aspects of her life I think it's sad to say she is not able to live independent and live alone…" (P4)

Poor judgement

The adult children also feel the need to assist their mothers because they feel the mental illness has resulted in the mothers having poor judgement. This following quote alludes to that:

"She earned her money but when it came to a point where she was in control of it she had to use it in a very ineffective way and threw money at the wrong places." (P4)

Safety

This decline in functioning mentioned above results in adult children feeling responsible for ensuring the basic daily needs of the mother are met. They feel that the mothers cannot be trusted to be capable of meeting these needs on their own due their mental illness. The daily needs included safety due to the mother's unpredictable behaviour as said in the following quote:

"You can't leave them alone during the day; you've got to have someone watching them 24/7 because you don't know what they are going to do. You don't know are they going to steal alcohol from you, are they going to kill themselves, you don't know are they going to hang themselves? You can't, you've got to watch their every move. You've got to give them medicine. You've got to hide stuff away. It's like looking after a child all over again. You can't just like go to the shop because you

don't know what can happen in that 5 or 10 minutes. You've got to plan your whole life around them. It's literally like having a baby." (P5)

"It's stressful because like I said you never know. The social worker can phone me now and say you mom is doing great, everything is fine, she is coping with everything. And two days later she can phone me and say you mom slit her wrists. So it is, it's very stressful as well. It's like going back to a child and being stressed about your toddler being at crèche, you never know if he is going to fall of a jungle gym or… you don't know." (P5)

Food

The adult children also felt responsible for meeting daily needs in term of food and nutrition as seen in the next quote:

"So when I go to work I must make sure there is something for her to eat for the whole day." (P2)

"Uuuuh my great concern is sometimes I normally go to work, before giving her the medication then it worries me a lot because most of the time I couldn't do breakfast for her, but I normally do 2-minutes noodles for her and I buy her most of the time jungle oats but I understand we have to change the menu but I couldn't monitor that because I have to wake up early and leave early in the morning." (P3)

Medication

The adult children also felt responsible to administer medication to their mothers. In a study done by (Aldridge, 2008) children of the mentally ill parents were found to be responsible for overseeing the safe and regular administration of prescriptive drugs to the mothers. This is what one participant said about the need to administer medication:

"You have problems of your own then suddenly you've this situation on the side. But you have to carry this weight making sure that ok even if I can go somewhere else, but I know 21h00, I'm supposed to be here so that I can give my mom her medication and make sure that she got something to eat earlier on." (P3)

Relapse

The participants felt the need to ensure that their mothers are adequately taken care of so that the chances of a relapse occurring are minimized. They related the story of an active relapse episode as being unpleasant and traumatic and them not willing to relive the experience. This is evidenced by the following quote:

"The situation that came across before she entered TARA I don't want that situation to happen again." (P3)

"Yes, because you know seeing my mother in that situation, I couldn't take it hey, that's why right now I'm saying I won't allow that situation to happen now, I'll just do each and everything, although I'm doing unnecessary things that I was not supposed to do but I'm making sure she's not going to that situation again." (P3)

Guilt

In a study done by (Aldridge, 2008) the children of the mentally ill parent were found to provide continued care through willingness or obligation because they felt they could provide more consistent, flexible and long term assistance. The participants in this study also felt obliged to take care of the mother. This is due to the feelings of guilt that come about when they feel they are not meeting the needs of the mother. This is evident in the next quote by one of the participants:

"So there is a lot of times when I'm like, I'm not going to phone her back, I'm not going to send it but I feel bad about it because at the end of the day she is still my mother. It's not just somebody that I'm helping out. It's my mother. She looked after me for how many years? Um ja it's difficult." (P5)

Perceived expectations

The feeling of obligation to take care of the mother also came from the perceived expectations that the adult children had about taking care of their mentally ill mothers. These are the expectations that they felt the mother and the society had about them taking care of their mentally ill mothers as seen in the next quotes:

"I feel like I don't want to have fun when I know my mom is needing my attention and I don't want to take too many risks of my life when I know she's alive and me as her oldest son should be there." (P4)

“And I feel like she should have planned of what she wanted with her future if something like this happened, like what type of care would she want. Would she want to be put in a home or would she want me to go through all these stressors that I go through when I’m with her or something. Some sort of arrangement. Now since she didn’t arrange that on time, I will have to stay with her and take care of her as the good daughter.” (P2)

Theme2: Time spent in caring for the mother

Lack of support

The adult children reported a great amount of time being invested in taking care of the mother. They attributed this in a lack of support available for as seen in the next quote:

“So I got stuck with my mom every Christmas, every December, all of that. And the other family they are just not worried, they are just not interested.” (P5)

Not asking for help

The time spent in taking care of the mother was also due to the fact that as much as the adult children yearned for support to be offered, they were not willing to let their needs known about their need for support in taking care of the mentally ill mother. This is evident in the next quote:

“My cousins were there, I know they are older than me, but I can’t put them in charge of my mother. They need to go out and they have their whole lives.” (P2)

Amount of time

The great amount of time invested in taking care of the mother was reported to be resulting in less personal time available for the adult children of the mentally ill mothers. This lack of personal time affected the goals of the adult children as they have less time to attend to them. This lack of personal time affected both the short term and long term goal. This is evident in the following quotes:

“It does consume a lot of my time looking after my mom in certain ways.” (P4)

“I can’t do anything else but stay with her.” (P2)

I need to live on with my life, I've got my commitments, I've got my relationship, and getting married soon. All of that took a backseat, trying to get my mum right." (P1)

"…to live with someone like her is going to take up my time taken away from my life and me having to study and have a normal life, therefore maybe having a negative impact on my future." (P4)

Theme 3: Effect on Relationships

Mother and friends or relatives

Living with a mentally ill mother was seen to be affecting different relationships in the life of the mentally ill mother or the adult children. The relationship between the mentally ill mother and her relatives was seen to be affected by the presence of the mental illness. This is seen in the following quote:

"This sickness is not something that anyone can deal with because people tended to dislike you most of them, including our neighbours because one thing that give me the strength, eeh some of my mom's friends and people who used to be close to her, they just scattered away when she started to be sick even including some relatives and so on but I started to be more engaged." (P3)

Mother and adult child

The relationship between the adult child and the mentally ill mother was also subjectively affected. It was either affected due to the decline in the mother's functioning because of mental illness, resulting in the mother not being able to contribute to the mother-child relationship in a way that is perceived to be normal by the adult child. This seen in the next quote:

"You know I just miss the normal mother and daughter relationship which I haven't had for a very long time and it's all because of this, because she just can't be, like I don't want to say normal, but it's not, she's not used to living like that. She is so used to hospitals, medication. In and out of psychiatric wards." (P5

The relationship was also reported to be affected by the role the adult child assumes in caring for the mother. This is evident in the following quote:

"She won't talk. My mother doesn't talk. She is an introvert, so with that, when she is sick she doesn't talk at all. So it's very difficult. So when I was still young I would

force her to talk to me. I would force her by screaming. I would yell and she would answer back, so like, we didn't have a very nice relationship because I would force medication on her, and sometimes I would push it down her throat. But we would always make up and get better". (P2)

Adult child and friends

The relationships between the adult children and their friends were also reported to be affected by living with a mentally ill mother. The adult children reported that they tend to isolate themselves from their friends due to the unpredictable behavior of the mentally ill mother which might result in embarrassment. Social life of children of mentally ill mothers is found to be affected due to the stigma associated with mental illness where the children felt alienated from the society (Almvit, Fjone and Ytterhus, 2009: 3). This is evident in the following quotes:

" I guess I am what's the word, isolated like lonely, I don't feel like, I don't know if it's because of my mom and yes it definitely because of my family situation, I feel like I don't want to be involved with someone even friends cause I know it will come about where they find out about the problem and the situation and I just feel, not embarrassing but it's not the same as if you have a happy family but I just feel it's a problem you know. I just don't feel like I want to express the reality of my situation to them that's why I don't make friends that easy."

Adult child and the father

The relationship between the adult child and the father was also reported to be strained due to the presence of the mental illness of the mother where the father is the husband or ex-husband of the mentally ill mother. The fathers were seen as being unsupportive of the mentally ill mother. This is seen in the next quote:

"There is some anger and blame I still have to towards my dad and it's something where it's up and down."(P1)

"And he (father) told me I'm not even going to come and do your wedding. He told me that. So I'm like "okay, fine". And there's too many emotions, too much pain. So I kind of postponed. And we decided we are just going to get registered." (P1)

Theme 4: Emotional Impact

Hopelessness

All the adult children interviewed reported to be affected emotionally by living with a mentally ill mother. They reported various emotions that arise from living with a mentally ill mother. The prominent feeling amongst the participants was hopelessness about the situation they find themselves in because of living with a mentally ill mother. This is seen in the following quotes:

"You know, I'm used to it. So I can't expect anything else. I don't know better. That's the life I'm used to."(P2)

"I don't think it's ever going to get better. It's never, she has been everywhere and it's never going to change. It's just, it either gets worse or it stays the same." (P5)

Sadness

The presence of the mother's mental illness in their lives was also reported to bring about sadness. This is evident in the next quote:

"…because this is not healthy, to be sad all the time."(P2)

Worry and Fear

They also expressed constant worry and fear for the safety of the mother due the mother's unpredictable behavior brought about by the mental illness. This is seen in the next quote:

"Uuuuh my great concern is sometimes I normally go to work, before giving her the medication then it worries me a lot because most of the time I couldn't do breakfast for her, but I normally do 2-minutes noodles for her and I buy her most of the time jungle oats but I understand we have to change the menu but I couldn't monitor that because I have to wake up early and leave early in the morning." (P3)

Anger

The participants also expressed anger towards the father for being unsupportive, and in some instances being blamed as being the perpetuator of the mental illness. This is evidenced by the following quote:

"Ja, just my dad's way about treating us and he doesn't have much sympathy, he doesn't take care, how's your mom been, can I help in anyway, so it's like we are all alone like he won't say a thing, we have to make the effort to feel good and come and be with my mom and make sure she's ok, if it were up to my dad my mom would be stranded alone and who knows what, you know….so its things like that I need to release and I get angry about how things could be much different you know…"(P4)

"There is some anger and blame I still have to towards my dad and it's something where it's up and down."(P1)

The anger about the mentally ill mother's behaviour is reported as seen in the next quote:

"And I get angry with her and I say we not like you that sits on the bed all day, and gets everything from everybody" (P5)

Irritation

The participants also reported finding themselves irritated by the behavior of the mentally ill mother although being aware that it is due to the mental illness. This is seen in the next quote:

"You get irritated because how can you be fine one day, the next day you are crying, you are miserable…" (P5)

Stress and frustration

Living with a mentally ill mother was also reported to be stressful and frustrating as the mother needed constant, ongoing care. This is evidenced by the following quote:

"I am at a point now where I don't want to talk about it; I want to move on because it has caused a lot of pain, a lot of stress and a lot of hurt. Sometimes talking is good but there's only so much that you can take."(P1)

Embarrassment

Embarrassment was also reported as a feeling that arises from living with a mentally ill mother by some of the participants. This is also reported in a study done by O'Connell (2008) on children of the mentally ill parents. The expression of the feeling of embarrassment by one of the participants is seen in the next quote:

“Obviously I would feel guilty for making her a prisoner in her own house and that’s embarrassing, that thing of sitting by the door, so people feel sorry for you. I didn’t understand it. I just didn’t feel good.” (P2)

4.5 Conclusion

In this chapter, the findings of the study were discussed. In the next chapter, the summary of the study findings will be made, and limitations of the study and recommendations will be discussed.

CHAPTER 5

5.0 DISCUSSION, LIMITATIONS, RECOMMENDATIONS

5.1 Introduction

In the previous chapter, the presentation of data literature control was discussed. In this chapter, the discussion of the findings, conclusions and recommendations together with the limitations of the study will be discussed.

5.2 Discussion of Findings

In this study it was found that taking care of the mentally ill mother and the issues around it was the most common experience among the adult children of the mentally ill mothers. They experienced the increased need of taking care of the basic daily needs of the mentally ill mother due to the mother's decline in functioning resulting in loss of independence and poor judgement. Mental illness is known to affect a person's functioning (Sadock & Sadock, 2007), which then results in decline or loss of independence and poor judgment at times.

With the mother's increased need for care, the adult children then find themselves responsible for taking care of their mentally ill mothers in different aspects such as safety, nutrition and administering prescriptive medicine. The need for ensuring safety was found to be due to the unpredictable nature of the mother's behavior brought about by the mental illness. The overseeing and regular administration of the prescribed medicine was found a responsibility among children of the mentally ill parents in a study done by Aldridge, (2008).

Some among the adult children found themselves responsible for ensuring the prevention of relapse of the mentally ill mother. The previous occurrences of the active episode of the mother's mental illness were reported to be unpleasant and traumatic for both the mother and the adult child. They were described as something worthy of putting all effort into, to eliminate their recurrence. The unpredictable nature of the mother's mental illness is the main source of the constant worry about relapse. It was found to bring negative effects in the study done by Tronsend (2011), where it was reported to bring loneliness, loss and sorrow.

Most of the adult children felt the obligation to take care of the mentally ill mother. In a study done by child (Polkki,Ervast & Huupponen, 2005) on children of the mentally ill parents, the children reported that it was their duty to take care of the mentally ill parent. This obligation was found to be due to the feelings of guilt of through the perceived expectations of the adult children about taking care of their mentally ill mothers.

The time spent taking care of the mother was found to be a prevalent concern. It brought about significant experiences of living with a mentally ill mother which were common among the participants. Some were concerned about the amount of time they invest in taking care of their mentally ill mothers. This was attributed to the lack of support in taking care of the mother. The adult children would themselves being solely responsible for taking care of the mother, without support from family members or relatives. This lack of support was due to family members not interested in helping but was also found to be due to the adult children not making their needs known about taking care of the mentally ill mother. Although they reported to be willing to receive support they also did not request the kind of support they need.

The amount of time spent taking care of the mentally ill mother resulted in less personal time available for the adult children. With this they experienced that their goals were being affect, both short term and long term goals. This is seen also in the study done by O'Connell (2008) where parental mental illness affected the social life of the child, where they are mostly withdrawn and asocial. In this study it is due to the time spent taking care of the mother, but in the studies mentioned it is due mostly to the fear of embarrassment from the mother's unpredictable behavior.

The adult children also experienced a negative effect on relationships significant to them or to the mentally ill mothers. First they reported the mentally ill mothers being alienated by friends and relatives that were previously close before the onset of mental illness. This affects the adult children because it results in the mother having to spend most of the time alone, needing the adult child to intervene by providing company. This then results in the experiences reported earlier where the adult child spends large amounts of time caring for the mother, with no support. This alienation of the mentally ill individuals was seen in a study done by Crisp, Gelder, Rix, Meltzer

and Rowland (2000) where people living with mental illness were perceived as unpredictable, dangerous and hard to talk to.

The mother-child relationship was experienced as being affected by the mental illness of the mother by some of the adult children living with a mentally ill mother. The adult children felt that the mentally ill mothers were not able to contribute in a way that is perceived as normal in the relationship. This was attributed to the presence of the mental illness. In a participant where the onset of the mother's mental illness was at an early age, the participant reported not knowing the person that her mother is, only the mentally ill version of her.

This reported effect in relationships is in line with the attachment theory that described the importance of attachment among human beings. The attachment theory states that the mental illness can diminish the caregiver's emotional response. This is reported by the participants where they do not perceive their relationships with the mentally ill mothers as being a normal mother-child relationship.

This effect on the mother-child relationship is seen as being due to the methods the adult children use in caring for their mentally ill mothers. These methods are perceived as being forceful to the extent of affecting the relationship. The necessity of the application of these methods is seen to be due to the uncooperativeness of the mentally ill mother while being taken care of.

The relationships between the adult children and their friends are also experiences as being affected. The adult children let friendships and social life take a back seat while caring for the mother becomes a priority. The adult children also choose to alienate themselves from the friends due to being embarrassed about the mother's mental illness and not wanting it to be known by friends. O'Connell (2008) also reports this effect in social life of the children of the mentally ill parents.

The relationship between the father and the adult child was reported to be affect by some of the adult children. These fathers were previously married to the mentally ill mothers and were divorced on in the process of being divorced the mothers. These fathers were seen as being unsupportive. They were also seen as being the perpetuators of the mental illness of the mother. Anger was a prominent feeling towards the father.

The emotional impact of living with a mentally ill mother was similar for some adult children, yet different in terms of what brings about those feelings. All these feelings stem from living with a mentally ill mother, but the specific aspects are different. The prevalent emotion was hopelessness about the situation of living with a mentally ill mother. Some feel that the situation is not going to improve from what it is, that the mentally ill mother is never going to get better, and the impact it brings is also going to stay with them. Amongst the feelings reported in a study done by Tronsend (2011) were the feelings of loneliness, sorrow and loss.

This hopelessness about the mother's illness was found to lead to sadness in the lives of the adult children living with a mentally ill mother. They reported pain and hurt from the way the fathers were handling the illness of the mentally ill mother. This led to anger towards the fathers of the adult children.

The adult children had the constant worry about the safety of their mentally ill mothers. This was due to the unpredictable behavior of the mentally ill mother. This led to frustration and stress for the adult children living with a mentally ill mother. The fear of the safety of the mother was also coupled with the fear of relapse as this was reported to be a difficult time for both the mentally ill mothers and the adult children living with them.

The findings of the study are consistent with the family systems theory that states that an effect in functioning of one family member is expected to impact other members in the family as a unit.

5.3 Recommendations

5.3.1 Assessment of needs

The mental health care professionals may assist the adult children of the mentally ill mothers while admitted in the hospital by consulting with them and helping them identify their needs in caring for the mother as it was evident in the study that even though they want the help in caring for their mother, they rarely make their needs known.

5.3.2 Identification of resources

The mental health professionals may also provide help by helping the adult children identify the resources available for them. This could be done by facilitating the

inclusion of other family members including the extended family members in caring for the mentally ill mother.

5.3.3 Education on relapse prevention

The adult children also spend time trying to ensure that relapse does not occur but also worrying as they are not confident of the effectiveness of their methods of relapse prevention. Being confident in administering effectiveness of the applied methods may lessen their worries about the occurrence of relapse in their mentally ill mothers.

5.3.4 Support groups

It may be beneficial for the adult children of the mentally ill mothers to belong to a support group. This may help them in realizing that they are not alone in their situation and may also help to minimize their distress. The mental health nurses could initiate these kinds of support groups in the mental health establishments.

5.3.5 Limitations of the study

All the interviews were conducted in English, while not all the participants were first language English speakers. This might have caused a decrease in the richness of data collected. Only five participants agreed to participate in the study, due to personal reasons and availability, however, saturation of the data was reached.

5.4 Conclusion

The results of the study show that the adult children living with a mentally ill mother have various experiences of living with a mentally ill mother. These experiences are more concerned with taking care of the mentally ill mother as the mental illness affects their ability to live independently. These experiences are perceived as negatively affecting the lives of the adult children as they impact on their personal lives and relationships. The study also shows that the adult children go through a turmoil of emotions while caring for their mentally ill mothers, which also negatively impacts on their lives.

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APPENDIX A:

INFORMATION SHEET FOR PARTICIPANTS: EXPERIENCES OF ADULT CHILDREN LIVING WITH A MENTALLY ILL MOTHER

My name is Nobuhle Makaula. I am from the University of the Witwatersrand, School of Nursing Education. I am doing a research on the experiences of living with a mentally ill mother for my Masters Degree in Psychiatric Nursing.

The overall aim of the study is to explore the experiences of adult children living with a mentally ill mother, with specific aims to look at the influence that living with a mentally ill mother has had on their adult children.

The information will be collected using semi-structured interviews where the participant will engage in a discussion with interviewer for a period not more than an hour. The interviews will be audio recorded with the permission of the participant.

The information collected will be kept confidential and will not be used for anything else other than for the research purposes. No names will be used in reporting findings of the research and any identifying information will be changed. The answers given by participants will be transcribed and analysed to find common themes and experiences. The transcribed information will be written up in the form of a report.

Permission to carry out this research was obtained from the University of the Witwatersrand Research Ethics Committee. An informed consent will be obtained from participants to conduct semi-structured interviews and to audio tape the interviews. Where the participant does not consent for audio taping the interview, written notes will be taken to record the interview. If audio recording is consented and conducted, the recording will be used for the purposes of this study only and will be destroyed after two years of the publication of the findings.

There will be no negative consequences for not consenting to participate in the study. There will be no compensation for participating in the study. Participation in the study is voluntary, during the course of the study you have the right to withdraw from the study at any time.

I will be happy to answer any questions you may have about the study.

npmakaula@gmail.com

Mobile: 076 311 8471

APPENDIX B:

EXPERIENCES OF ADULT CHILDREN LIVING WITH A MENTALLY ILL MOTHER

CONSENT FORM FOR RECORDING OF SEMI-STRUCTURED INTERVIEW

I have been given the information sheet on the project entitled: Experiences of adult children living with a mentally ill mother. I have read and understood the information sheet and all my questions have been answered satisfactorily.

I understand that I can decide whether or not the interview should be recorded and that there will be no consequences for me if I do not agree for the discussion to be recorded.

I understand that the information from the recording will be transcribed and transcripts will not include my name. I understand that if the interview is recorded, the recording will be destroyed two years after publication of the findings.

I understand that I can ask the person interviewing me to stop the interview altogether at any time.

I consent voluntarily for the researcher to record the interview.

Participant's signature: _____ Date: _____

Interviewer's Signature: _____ Date: _____

APPENDIX C:

EXPERIENCES OF ADULT CHILDREN LIVING WITH A MENTALLY ILL MOTHER

CONSENT FORMS FOR SEMI-STRUCTURED INTERVIEWS WITH PARTICIPANTS

I have been given the information sheet on the research project entitled: *Experiences of adult children living with a mentally ill mother.* I have read and understood the information sheet and all my questions have been answered satisfactorily.

I understand that it is up to me whether or not I would like to participate in the semi-structured interview and that there will be no negative consequences if I decide not to participate . I also understand that I do not have to answer questions that I am uncomfortable with and that I can stop the interview at any time.

I understand that the researcher will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else. I consent voluntarily to participate in the interview for this study. I have been given telephone numbers that I may call if I have any questions or concerns about the study.

Participant's Signature: _____ Date: _____

Interviewer's Signature: _____ Date: _____

APPENDIX D:

Interview 2

Interviewer: Good afternoon maam

Interviewee: Good afternoon maam

Interviewer: My name is Nobuhle and I'm doing my Masters at Wits about the experiences of living with a mentally ill mother. So this recording that I am doing here, I'm going to transcribe it and present the report at Wits University and the recording will be kept for two years and then it will be destroyed. So I'm just going to ask you to share with me what has been your experience of living with a mentally ill mother.

Interviewee: Well, um, my mom was diagnosed with schizophrenia, but I was still, I was 7 then, so I wasn't really aware of what was happening. I started understanding what was going on when I was a teenager. And let me just say '97 she got diagnosed, 2000 my parents split. So I was staying with both my parents and they were married, so we lived in my parents' house and my granny was taking care of my mother from 10 years till 13 years. And then she died. And then from 13 years it was just the two of us. She was, um, since she left her marriage she would go to school but she wasn't teaching anymore, she would just sit in class and do nothing. And the principal would tell me. I was actually going to the same school that she was teaching. She told me I should tell my mother to stay at home and not come to school anymore. And then she would stay at home. But, like, 2005 was when I started to take her to hospital and making sure that she was taking her medication. She was still a teacher but she was incapacitated. She was still on the payroll system. So that's why she started going to hospital. And I was still in grade 10 then. And she started taking medication and she got better, she got better so much that she went back to school and she started teaching again. When I went for my first year she promised me that she would stay and take her medication because I was staying in Mpumalanga so I had to come this side and study at Wits. So I left home my first year and when I went back she had relapsed. I took her to hospital again to get her stabilised. But I knew I could not be there to make sure she takes her medication. My cousins were there, I know they are older than me, but I can't put them in charge of my mother. They need to go out and they have their whole lives. She still wasn't taking her medication. So at second year, one of my cousins called me and she is like, "your mom is not coming out of the room, she hasn't come out in a week now and I don't think she is eating". So I went and I got her. She was very skinny, and I could see that she wasn't eating. I could see that she was not well again. So that's when I took her to Joburg Gen this side and that's when she got admitted and got helped. After that she came here (Tara Hospital). When she finished the program here one of my aunts took her because she didn't want me to get her a placement for her. She went to stay with her for a few months, but while

she was there, my aunt is very traditional, she believes that my mom has been bewitched and all sorts of things. So she was not taking her medication again. I started staying with her, I bought a house, and we were staying together, and I knew that it was difficult for her to take medication on her own so I got, I had the medical aid she started taking medication. She was on an injection once a month and that was easy for us, until last year when I didn't have medical aid anymore and she did not want to her medication anymore and I had to get her admitted again.

Interviewer: So it sounds like there has been a lot of...

Interviewee: Yes it's been a lot. My dad is crazy too so both my parents are mental. But I don't stay with them. He is staying alone in Mpumalanga. When did I see him? I saw him in March. I went to visit him, his place was upside down. He is not on any medication. He is on weed and he is not taking care of himself. And I can't take both of them and take care of them.

Interviewer: So both your parents need a lot of help from you.

Interviewee: Yes

Interviewer: So now, how has this impacted in how your life has turned out to be?

Interviewee: I wouldn't say it's my mom's illness. It's the department's fault. I was studying and I had to leave because they cut my mom's salary. And I had to work and it was that time when she was staying with my aunt and she didn't like staying there. She was pulling all sorts of stunts, she wasn't eating, she was doing the same, saying she wants to stay with me. So I left school, I went to work at the airport. I was a flight attendant so I could have finished my degree by then or something.

Interviewer: And now when you think about all of that?

Interviewee: No I'm still, I'm only 25 so, right now I'm changing careers though. I want to be pilot now. When I left the airport I went to do something else and it paid quite more than what I was getting at the airport so I wanted to start doing lessons on flying so I started doing my PPL. But I'm waiting for that money so I can finish that. And I think I'm quite fortunate because my mom was working most of her life since 1985 so that will help me.

Interviewer: Oh, you mean the pay-out from the department?

Interviewee: Yes

Interviewer: And when you think about her life, what it was, and what it is now?

Interviewee: I don't know who my mom is anymore. I don't know who she was. I just know the sick version of her.

Interviewer: Were you young before she...

Interviewee: She got better in 2005 and she went back to school. But I don't know if that's her. She was fine, she was going to school but she never, we've never been like other people. Mother daughter relationship-wise.

Interviewer: So what would you say is different with you guys when you say different?

Interviewee: She won't talk. My mother doesn't talk. She is an introvert, so with that, when she is sick she doesn't talk at all. So it's very difficult. So when I was still young I would force her to talk to me. I would force her by screaming. I would yell and she would answer back, so like, we didn't have a very nice relationship because I would force medication on her, and sometimes I would push it down her throat. But we would always make up and get better.

Interviewer: So are you saying you saying you would always make up?

Interviewee: Yes, she can't stand it. She would say she is sorry and I would also forgive her and make up and we would be fine again. But it's not like other people.

Interviewer: And you think mental illness played a role in that?

Interviewee: Yes

Interviewer: And how would you envision the relationship if she never got sick?

Interviewee: A better one. I believe she could have told me, I've made mistakes as well. I believe she could have guided me. She could have told me what was lying ahead of me in my life. I had to learn that by myself. Not even my aunties told me. So I had to find myself to adulthood from teenage hood.

Interviewer: So you mean that even though she is there as a mother, there is a lot she couldn't do for you?

Interviewee: I do more for her than she does for me.

Interviewer: Which makes it not to be a normal mother daughter relationship like you said before?

Interviewee: Silence

Interviewer: And I see this is emotional for you.

Interviewee: Yes…Silence

Interviewee: And no one has asked me how I feel. No one asks, it's always about her. Even my family members now they are blaming me for taking her to Randfontein. And they know very well that there is no one that can care for her. It's like I deserted her, I don't want anything to do with her anymore. But I think it's the best when she is there. I would go and see her every two weeks. And I am fine with

that arrangement, when I am there we don't talk much. We just sit, and I have to come up with subjects. And she answers with one word answers.

Interviewer: And when that happens, what comes to your mind?

Interviewee: You know, I'm used to it. So I can't expect anything else. I don't know better. That's the life I'm used to.

Interviewer: Which makes me think of what you said earlier that you, sort of, do not know the real her and that you know her as...

Interviewee: And the stories that she tells me, sometimes I just brush them off, because I just feel like she wants me to join her in her little world.

Interviewer: What sort of stories would she say?

Interviewee: That she wasn't born, she just came from nowhere, my friends are not who I think they are. And I've got these little kids that come to visit me, one is 3 and one is 6. She doesn't like them, she says they are adults, they are not kids. I don't know what it's going to be like with my kids if she does not like those ones. She says they are not kids they are adults, they are just pretending to be kids.

Interviewer: Which doesn't sound normal to you?

Interviewee: Yes. And I know that that if I get married, I will have to stay with her. I will have to find a husband that is going understanding of all her tricks, the stunts, everything she pulls. I think I know her better than anyone. And I know that she can do things just for attention or like when people are come to visit she would pretend like she is sleeping. And I know that she is not sleeping. She is just avoiding confrontation. So all those things I would need to find someone who can put up with that.

Interviewer: So it seems like you have been thinking about her condition is going to affect you even in the future.

Interviewee: And I feel like she should have planned of what she wanted with her future if something like this happened, like what type of care would she want. Would she want to be put in a home or would she want me to go through all these stressors that I go through when I'm with her or something. Some sort of arrangement. Now since she didn't arrange that on time, I will have to stay with her and take care of her as the good daughter.

Interviewer: So it sounds like you are saying that as much as you are doing these things that you are doing for her, you are not sure if she appreciates it.

Interviewee: Well, she doesn't appreciate anything I do for her. She says all the negative stuff about me when she is with her sisters. And she is not understanding right now I have financial troubles that is why she went there otherwise I could have

been staying with her. And every time I'm here she says put a discharge, and it's so annoying. And I told them that is what my mom is saying, and could they please make her understand.

Interviewer: And you feel like she still does not understand?

Interviewee: Yes. She does not believe me.

Interviewer: When you say?

Interviewee: About everything, like, even now I told her what is happening with the money, she wants to go to the department herself, to speak to them and everything. She thinks I'm eating all her money. She thinks that they paid her a long time ago, and I just put her away because I want to chow her money.

Interviewer: When you talk to her, what is her opinion about this whole thing?

Interviewee: She loves brushing things off so she looks normal. I would try and explain to her what is happening and everything and she would say no it's fine. And then she would be like, did you write the discharge, which means she didn't understand a word I said.

Interviewer: And when you ask her where she would rather be?

Interviewee: I asked her and she said she would stay at my granny's house. We've tried it before and it never worked out.

Interviewer: I heard you mention earlier that you are only 25, things are just starting out for you, with your career you are you are redirecting...

Interviewee: I was late though because I finished my matric early when I was 16 years old.

Interviewer: What was your plan initially?

I wanted to finish my degree. And practice psychology because that is what I was doing.

Interviewer: And you said you had to stop that because she got sick and you had to go to Mpumalanga.

Interviewee: Yes she got sick and I didn't have money anymore and she needed to stay with me.

Interviewer: And when you moved back to Mpumalanga?

Interviewee: No we were staying at Kempton Park, I was working at the airport. I rented a place and then I bought a house which I lost last year.

Interviewer: What happened there?

Interviewee: I had to sell it otherwise they would repossess it. We sold it at a loss.

Interviewer: You lost your job?

Interviewee: No. After I left the airport I went to work at Bryanston. But at that time I didn't have a job.

Interviewer: Oh so you were in between jobs?

Interviewee: Yes

Interviewer: So that was just the end of the job, 9t had nothing to do with your mom?

Interviewee: Yes but my mom would not have relapsed if I had a medical aid. Because she was on injection so…

Interviewer: So you mean if you were still working you would have carried on with your medical aid.

Interviewee: Yes.

Interviewer: So now it sounds like everything is impacting on another.

Interviewee: Silence….sigh…

Interviewer: So it sounds like it's been quite a journey.

Interviewee: Yes it's a lot. And I have my own personal life. I have to live.

Interviewer: And how is your mom's illness affecting that?

Interviewee: She doesn't like some of my friends. And when I stay with her I can't do anything else but stay with her. Like last year when I was working at the airport I would lock her in the house and go to work because there's many instances where my mom would just leave the house and I didn't know where she was and I would look for her all over and she would tell me she just wanted to go and do some shopping or whatever or to do her hair and I'm like aah aah I can't be stressing about that so I would end up locking her in the house every time I go to work. That is not nice; I know she doesn't like it. And she would just sit by the door with the burglars open so that people feel sorry for her and my friends would ask me what is happening, why is she by the door and you know…

Interviewer: And what sort of feeling would that bring to you when you were doing that?

Interviewee: Obviously I would feel guilty for making her a prisoner in her own house and that's embarrassing, that thing of sitting by the door, so people feel sorry for you. I didn't understand it. I just didn't feel good.

Interviewer: So it sounds like even when you would stay with her at your place it was still a challenge.

Interviewee: Yes unless if I were to leave or get someone to stay with her while I was away. Or maybe if I can lock the gate and she can just… because she loves talking alone outside in the yard. So it's better. But I could lock the gate there.

Interviewer: So that was during the weekdays when you were working?

Interviewee: Yes I had to, when my mom cooks she burns the food, or she throws it away because there is stuff in it. So when I go to work I must make sure there is something for her to eat for the whole day, and need to check the bins if she is throwing it away. But she is smarter now she is flushing it in the toilet so I wouldn't find it (laughs).

Interviewer: So there's food going to waste also?

Interviewee: And when I wasn't working she would throw away food that we actually needed, and I would force her to eat it, and she would say she doesn't want it, she wants whatever, or she doesn't eat this brand and whatever the case may be.

Interviewer: You were not working at the time?

Interviewee: No. she doesn't understand the situation even if you explain. (tearful)

Interviewer: And on the weekends, how would things be?

Interviewee: You mean if we stay together again?

Interviewer: Yes, no I mean you described how the day would go when you were working during the week, and over the weekends?

Interviewee: I was working at the airport so most of the time it's not really off on weekends. Sometimes I would go to work in the evenings and I would be home the whole day. And it would be difficult when I go on night stops because I know that I will be away maybe for two nights. So I would call her and ask her what she ate and everything. So it wasn't a matter of weekends. When I was working in Bryanston I would leave her like during the week to Sunday school class, and on Sundays we would go to church together. And when we go to church people are very nice to her and everything but she looks at them funny, she doesn't talk to some of them. Its just that she is very rude.

Interviewer: And when you observe that kind of behaviour?

Interviewee: They are used to her now.

Interviewer: They understand her?

Interviewee: Yes

Interviewer: When you take her to new settings?

Interviewee: We go to the mall together and she would just do a funny thing, like the other day we went shopping and then went to the till and she just faced the other way and I, she loves doing things and I just turn her the right direction. She is fine but she can't make decisions, like "do you want this one or this one", she doesn't know what she wants.

Interviewer: So you end up making those decisions for her?

Interviewee: Yes

Interviewer: So from here…

Interviewee: She doesn't have any friends. I'm the only one she has.

Interviewer: The one she had before?

Interviewee: In Mpumalanga, her colleagues she didn't like them, and that was the last time she saw them.

Interviewer: But before her sickness did she have normal relationships?

Interviewee: They would actually come to visit her when she was at home.

Interviewer: Do you think her condition has impacted the kind of relationships you have in any way?

Interviewee: Yes because even if you go there with a friend, she wouldn't talk, she doesn't start a conversation and sometimes she doesn't answer.

Interviewer: So do you have to think before taking someone home?

Interviewee: Yes, and she is different with everyone, you might go to her and she likes you. And when I take someone else she acts somehow with them.

Interviewer: So what sort of reaction do you get from your friends when they meet your mom.

Interviewee: No my friends know. I even tell them in advance what to expect and they will say oh she is not that bad or whatever, just to make me feel better.

Interviewer: I heard you earlier describing the kind of husband you would need if you were to settle down. So have you had any encounters where you were trying a relationship out and due to her illness you felt like it won't work?

Interviewee: Well, my ex, I don't think it was her illness per se but I don't think he would have handled it. It was going to be a bit too much for him.

Interviewer: What made you think of that?

Interviewee: Staying with a mother in law and her acting like she and having your wife to babysit her all the time, I don't think I would want that as a guy.

Interviewer: Did he know you felt this way? Or was it other things that separated you?

Interviewee: Yes it was our own things. I never even introduced him and he was mad about that as well. I didn't know how my mom was going to react when meeting someone who is very important to me. I am seeing someone now but I think he would understand him better than anyone because he is a doctor, but it's not serious but I think he would understand her better because he knows the nature of the illness.

Interviewer: So have you thought about introducing him?

Interviewee: No, not now, it's still new, when the time comes, yes. He is going to be understanding. Even now he has promised me, I'm on Epilim, he has promised me that he is going to give me at my door step for the rest of my life regardless of me marrying him or not.

Interviewer: What are you on Epilim for?

Interviewee: For bipolar.

Interviewer: When were you diagnosed with bipolar?

Interviewee: Last year but I wasn't taking medication. I don't want to be on medication.

Interviewer: And you being diagnosed with bipolar, do you think it had anything to do with your moms illness?

Interviewee: I don't know if I'm going to go crazy or if I'm crazy as it is.

Interviewer: But do you think her illness had anything to do with it?

Interviewee: I think so, because this is not healthy, to be sad all the time.

Interviewer: And where does this sadness come from?

Interviewee: From everything that happens on a daily basis (tearful).

Interviewer: I see this is a sensitive and emotional topic for you. So if you need counselling or you need someone to talk to we can arrange a meeting with my supervisors at wits. Do you think you would need that sort of help?

Interviewee: I've tried counselling it doesn't help. You just talk, talk, talk, and cry, cry, cry and nothing happens.

Interviewer: So if you think about what is happening now, what do you think would help you?

Interviewee: I don't know hey, I haven't thought, I don't even think medication would help, it just has to be a miracle.

Interviewer: So when you think about help, nothing comes to mind?

Interviewee: I don't want counselling and I don't want medication, so those are the options that are there that have been proposed to me. For someone in my situation is there anything else?

Interviewer: That might need to be explored.

Interviewer: Well, if at any stage if you feel like you need someone for counselling then I would refer you to my manager or my supervisors, but thank you so much for sharing such sensitive information with me, I really appreciate it.

APPENDIX E:

R14/49 Ms Nobuhle Makaula

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M130735

NAME: (Principal Investigator)	Ms Nobuhle Makaula
DEPARTMENT:	Nursing Psychiatry University of Witwatersrand Tara The H Moross Centre
PROJECT TITLE:	Experiences of Adult Children Living with a Mentally Ill Mother
DATE CONSIDERED:	26/07/2013
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Annalie van den Heever
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	14/08/2013

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX F:

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

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South Africa

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14 May 2013

To Whom it May Concern

Re: Nobuhle Makaula's application to do research at Tara

Ms Makaula applied to do her research entitled, **"Experiences of Adult Children Living with a Mentally Ill Mother"** in April 2013.

We acknowledge receipt of this application, and it should be approved at our next Research Committee meeting. She will only be able to start her research, once she is in receipt of Wits Ethics Approval as well.

Yours sincerely

p.p.

Dr Jow'hara Chundra
FCPsych(SA)
Secretary- Tara Research Committee

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