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FERNANDA RIPPEL DE SOUZA

**EXPERIENCES OF SIBLINGS OF YOUNG PEOPLE WITH A
MENTAL ILLNESS**

Porto Alegre

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ABSTRACT

Background: Following the deinstitutionalisation of mental health services across Australia, the burden of care for people with a mental illness has fallen to a large extent to family caregivers. Research has shown that families struggle with access to appropriate mental health services and acquiring adequate and appropriate information and support. Mental illness is often diagnosed when the person is in adolescence and this has a great impact on the family and, in particular, siblings.

Aim: The aim of this project was to explore the experiences of siblings of young people with a mental illness.

Method: Individual in-depth semi-structured interviews were undertaken with six participants. Data were analysed using thematic analysis.

Results: Four main themes emerged from the data: Lack of Support; Tacit approval for inappropriate behaviours; Being Anxious; The fabric of the Family. Subthemes were identified within each theme.

Conclusion: Participants in this study need information and support, they protect and advocate for their sibling, they tend to be anxious and cautious and there are changes within the family that are life long. Better information about services and specific programs designed for siblings such as peer support programs would be helpful.

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Chapter 1

Introduction

Mental health problems are a growing concern across many countries. This chapter will outline the context of the study as it relates to mental health in general, mental health in Australia and in the state of Victoria. The concept of Mental Health for this study will be explained and an overview of how mental health services work in Australia and particularly the state of Victoria. The aim, research questions and significance of the study will be defined and the thesis outlined.

Mental Health

It is essential to define the concept of mental health in order to understand everything associated with it, such as the consequences of mental illness for individuals, families, the community and the environment.

“Mental health is defined, by the World Health Organization, as a state of well-being in which the individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community” (WHO, 2014).

Recent reports (Australian Institute of Health and Welfare (AIHW), 2007) show that although the real causes for the development of mental illness are not known, it is possible to prevent mental illness by observing the factors that might contribute to the process. There are risk factors and protective factors. Risk factors include socioeconomic disadvantage, bullying and physical, sexual and emotional abuse. They enhance the probability of mental health problems occurring. Protective factors such as economic security, good physical health and involvement in community groups prevent the occurrence of mental health problems or reduce the potential

negative effects of risk factors (Australian Institute of Health and Welfare (AIHW), 2007).

The notion of preventing the onset of mental illness is one of the main reasons for developing strategies within the health system to provide the population with adequate and appropriate resources to maintain their wellbeing. The knowledge of how mental health impacts the life of the family of people with a mental illness and the consequences to the community and environment is key in planning those strategies (Commonwealth of Australia, 2009b).

Some studies (Chen & Lukens, 2011; Mak & Cheung, 2012; Murray-Swank et al., 2006) explore the burden on the families of people with a mental illness and how mental health services provide support to these people, but little is known about siblings of young people with mental illness and the consequences on their lives (Lukens, Thorning, & Lohrer, 2002).

Mental Health in Australia

Australia is one of the largest countries in the world with a land area of approximately 7.692 million square kilometers and a population around 23.5 million people (Australian Bureau of Statistics, 2015). The country is a Federation and is divided into six states and two territories. The health system is somewhat different in each jurisdiction (Australian Government, 2015). This study will take place in the state of Victoria.

In the 1980s, the government of Australia in a collaborative agreement with health professionals and consumers created a plan to guide a change in national mental health services called National Mental Health Strategy. This strategy was structured around four major documents:

- The National Mental Health Policy in which were defined the broad aims and objectives that would guide this reform;
- The National Mental Health Plan, a five-year plan to achieve these goals;
- The Mental Health Statement of Rights and Responsibilities, where it was described the civil and human-rights for the strategy, and
- The Medicare Agreements, to organize funding provisions to support the reform (Meadows, 2012).

One of the most important changes that was proposed with the first National Mental Health Strategy was to shift services from institutions to local communities following a non-systematic trend that was occurring all over the world due to economic and political issues. This process was called deinstitutionalization and resulted in a number of social consequences because the responsibility for in-patients moving from institutions and psychiatric hospitals to the community, most impacted the families of these individuals with mental illness (Rosen, 2006).

Nevertheless reform of mental health services nationally has been slow. Prioritizing mental health promotion through community education, preventing the development of mental illness through early intervention, guaranteeing of the rights of people with mental illness and good quality support for their families continues to encourage

policy makers on organizing new programs and service (Victoria State Government, 2014).

In Australia, almost half of the population will experience some lifetime mental disorder, according to the National Mental Health Report conducted in 2013 (Commonwealth of Australia, 2013). Of these people, one in five, (20%) experienced the presence of symptoms in the twelve months prior to the survey. The common disorders identified were: anxiety disorders, affective disorders and substance use disorders. The most disturbing data identified in this survey were the higher rates of prevalence of mental disorders among young people. 26% of people aged between 16 and 24 years presented with an episode of mental disorder in the twelve months prior the survey (Australian Institute of Health and Welfare (AIHW), 2007). It was also found that substance use disorder was higher than in the general population with 13% of young people presenting with this problem in the previous twelve months compared to 5.1% in the general population (Commonwealth of Australia, 2013).

Mental Health in Victoria

In Victoria, the Mental Health Directorate has control and regulation of services. At the instigation of the National Mental Health Strategy, Victoria took longer to implement the strategy than other states of Australia and therefore the consequences were later to be seen. Services remained institutionally based for longer than in other states such New South Wales. When they were finally ready to change it was in a systematic manner, so in Victoria, all independent psychiatric hospitals were closed and replaced with community based mental health services (Rosen, 2006).

Following the Fourth National Mental Health Plan, new directions for the Victorian mental health system included systems for continuity of care and early intervention programs (Commonwealth of Australia, 2009a). The current National Mental Health Plan addresses three age bands: child and adolescent (0 – 18 years), adult (16 – 64 years) and aged persons (65 years and older). This separation aims to increase the efficiency and effectiveness of treatments and maintain a life-span approach to care. Exceptions within the age bands are permissible, such as in the case of teenagers who develop early or older people who still possess the vigor of a younger adult (Victorian Government Department of Human Services, 2006).

Apart from the age groups, the health care system itself is organized in what are called “catchment areas” (Victorian Government Department of Human Services, 2006). These are geographical divisions that establish which populations will be best served by which facilities and staff, as well as to organize funding. Importantly, there is no impediment for the delivery of services to people who present at another catchment’s facilities, but the organization of the system as a whole encourages people to seek services in their own catchment area (Victorian Government Department of Human Services, 2006).

At present, Victoria has 13 child and adolescent services, 21 adult services and 17 aged persons’ services (Victorian Government Department of Human Services, 2006). These centers operate in different ways: for example, children are usually brought to health services by their parents; but teenagers may hesitate to seek out help, so that the health system may need to reach out to them. In general, children and teenagers

with mental health issues do not need specialist services, so primary care services attend to them (Victorian Government Department of Human Services, 2006).

Adult mental health services are focused on people with major mental illnesses or disorders, such as schizophrenia or bipolar affective disorder. It is also important to note that a number of people will experience crisis from time-to-time, which can lead to risk of harm to themselves or others. Another important point regarding adult mental health services is that due to the wide range of ages embraced by this age band, services need to be flexible: older adults could have the focus of their health care on the management of symptoms, whereas younger adults may also require treatment focused at helping them continue their personal growth and development. Aged persons mental health services must address the additional complexities of the ageing process and its impact on mental health (Victorian Government Department of Human Services, 2006).

The mental health system has integrated facilities. Consumers are generally managed by community caseworkers using a continuing care strategy. The case manager will also adopt specific measures on a case-by-case basis, such as pharmacological treatments, psychological and other therapies and psychosocial rehabilitation. Treatment planning is a legal requirement and is focused on identifying the changes (short and long term) required to return the care of the consumer to less restrictive community based services. Consumers, family and other caregivers are encouraged to be actively involved in the planning process (Victorian Government Department of Human Services, 2006).

Consumers may also need crisis services or inpatient care occasionally. Following an acute inpatient admission, consumers may need to spend some time at a prevention and recovery care (PARC) service before going home (Victorian Government Department of Human Services, 2006).

Consumers discharged from mental health services are normally referred to the care of other service providers, and they are therefore included in the treatment plan. Typically, planning includes the person's General Practitioner (GP), as they can provide ongoing treatment, monitoring recovery and relapse prevention. The GP is expected to engage with the treatment plan to avoid, minimize or at least plan for re-entries to specialist mental health services (Victorian Government Department of Human Services, 2006).

Mental health services are provided by two interrelated groups: clinical services, which are funded to develop and practice evidence-based clinical care which engage directly with the public (including state-wide services for particular clients in regions spanning multiple area mental health services) and Psychiatric Disability Rehabilitation and Support Services (PDRSS), which assist consumers and caregivers throughout the recovery process (Victorian Government Department of Human Services, 2006).

Other supports for people with mental illness and their families

A number of non-government organisations have been developed to support people with mental illness and their families and loved ones. The Mental Health Foundation of Australia (Victoria) is the oldest of these, founded in 1930. It is an association of

professionals, consumers, families and related organisations interested in mental health as well as members of the general public.

Likewise, COPMIA is an enterprise aimed at children who have a parent/s with a mental illness or addiction. The COPMIA guideline for all New Zealand mental health and addiction services describes the expectations and makes suggestions for services engaging with children and families. The guideline emphasises assets, and encourages and protects the security and rights of children.

The Australian and NZ mental health association offers information about mental health to the general public; develops mental health skills to interested people including patients, consumers and carers; educates and trains professionals in mental health practices; researches and develops knowledge in the field and promotes better mental health and mental health services.

Mental Health Carers ARAFMI Australia is a group of organisations whose participants are mental health carers. They propose the opinions and viewpoints of carers and fight for services to improve the lives of people with a mental illness, as well as carers and family members.

The Mental Illness Fellowship of Australia provides services and programs to people with a mental illness, their families, friends and carers. The services are community-based, therefore enable people to stay well for longer, remain connected with their family, friends and community, and achieve a better quality of life. In addition, these services are more cost effective than formal mental health services.

Programs are aimed at supporting people in the crucial areas of their lives: home, work and relationships. Opportunities are generated to connect people with education and employment prospects, to find and create homes linking them with their communities, and to foster strong relationships with families and friends.

SANE Australia operates for improved lives for people with a mental illness. It does this through community education programs, research and campaigning for better services and mind-sets.

Significance

Mental illness is commonly diagnosed when people are young. The impact of mental illness is profound not only for the individual but also for the family members involved. Being a brother or sister of a person with mental illness brings with it other issues. As many of these siblings will also be young, their confidence and competency in dealing with symptoms, signs and behaviors associated with having a brother or sister with a mental illness may be inadequate (Australian Institute of Health and Welfare (AIHW), 2007).

It is important to know how a mental illness affects a sibling's ability to manage interventions in ways that help their brother or sister with mental health issues to be part of the family, and to manage their own anxiety levels and personal life.

Research aim and questions

The purpose of this study was to explore the experiences of siblings of young people with mental illness in the state of Victoria, Australia. The study sought to answer the following research questions using a descriptive qualitative framework:

- What are the experiences of young people as they discover their brother or sister has a mental illness?
- What are the experiences of siblings as they engage mental health services?
- What impact does having a brother or sister with a mental illness have on the person?
- How can the brother or sister of a sibling with a mental illness be empowered whilst caring for their sibling?

Structure of the thesis

The thesis is divided into five chapters. Table 1 provides a description of the structure of the thesis.

Table 1. Structure of the Thesis

CHAPTER	CONTENTS
1. Introduction	This chapter provides the background to the study, mental health services in Australia and in the state of Victoria. It describes the significance, aims and research questions of the study.
2. Literature Review	Chapter two presents relevant literature on mental illness, the process of deinstitutionalization and caregiving for people with a mental disorder. It also identifies the need for further studies on experiences of young persons who have a sibling experiencing a mental illness.
3. Methods	This chapter discusses the design chosen for the study and the justification for why it was chosen. The chapter also describes the study setting and how participants were recruited. Data collection methods are discussed including the processes for data analysis. Ethical considerations related to the study are also presented.
4. Findings	Major findings from the study are presented in this chapter addressing the key themes identified during data analysis.
5. Discussion, Conclusion and Recommendations	This chapter discusses the key findings in relation to the research questions and offers recommendations, implications for practice, research and education. The

	chapter also highlights the strengths and limitations of the study.
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Chapter Summary

This chapter has provided an overview of the study including the background of the study, the aim of the study as well as the research questions the study will address.

Chapter 2

Literature Review

This chapter examines the literature regarding mental illness and in particular, siblings. It discusses the definition of mental illness and its impacts on the individual with the diagnosis, his/her family and society; the outcomes of deinstitutionalization; caring for a person with mental illness and the associated issues that come together and highlight what is known about the experiences of siblings of people with a mental illness.

The search for literature was made through Monash University Library website and scientific databases such as Ovid Medline CINAHL and PubMed. The key search terms used were Mental Illness, Siblings, Australia, Deinstitutionalization, Caring and Mental Health. Some of the articles were discovered based on the references list of articles found previously by searching the databases.

Mental Illness and Deinstitutionalization

Mental illness, also known as mental disorder, is a generic term used to describe a group of problems that compromise the mental state of an individual affecting the way he/she feels, thinks, performs and interacts with other people. There are many types of mental illness and they are characterized according to the symptoms that the individual presents. The most common mental health problems are depression, anxiety, schizophrenia, bipolar affective disorder, personality disorders, and eating disorders. The severity of the symptoms and levels of distress as consequence of a mental illness are different and individual for each person and they are important

clues to the health team when planning the best approach for each person (Commonwealth of Australia, 2009b).

Diagnosing a mental illness is the first essential step to prepare an appropriate plan of action, to determine if the person needs treatment, the nature of that treatment and the possible outcomes of the illness and associated treatment. To diagnose a mental illness it is necessary to assess symptoms and signs. Usually this is assisted through the use of systems to categorize the symptoms for each disorder and the criteria needed for diagnosis. One such manual to guide diagnosis is Diagnostic and Statistical Manual of Mental Disorders, now in his fifth edition (DSM 5), edited by the American Psychiatric Association (APA) (American Psychiatric Association (APA), 2013)

The diagnosis of a mental illness is just the beginning of a journey that in many cases will continue across the lifespan of a person, contributing to various levels of dependence on others in times of crisis or because of disabilities. Numerous symptoms of mental illnesses emerge during adolescence and even when they are diagnosed in adults many have links to childhood/adolescent problems (Australian Institute of Health and Welfare (AIHW), 2007).

Throughout history there were many ways that society and governments dealt with the consequences of mental illness in society. In many cases, because of the stigma of being associated with a person with mental illness, people were marginalized and sent to institutions far away from their family and society for care and treatment (Killaspy, 2006). This was the most common system for managing mental health problems in

the western world until the 1950s and the beginning of the movement against institutions based on studies showing that the model was deficient (Killaspy, 2006).

Whilst the idea of deinstitutionalization began in the 1950s, it took longer to be visible in the practice, and only in the early 1970s was policy created that articulated for the first time plans to change the model from institutions to community-based care. According to Mansell (2006) in North America, Europe and Australia there was widespread implementation of the change with the closure of many residential institutions to be replaced by community-based services (Mansell, 2006). The most advanced countries at the moment are Sweden and Norway where all the institutions have been replaced by community-based facilities (Mansell, 2006).

The deinstitutionalization of people in mental health services was a social attitude with the intent of improving care for people with mental health problems, based on many studies that demonstrated that excluding people from the social environment and being apart from family did not produce good outcomes for people with mental illness (Mansell, 2006).

However the process of deinstitutionalization created significant other issues such as the need for new accommodation for people, facilities to support the continuation of treatment, health professionals with community experience to provide interventions for those still requiring attention, mechanisms to reintegrate people back to the community and importantly, the expectation that families would take on a greater amount of the care and responsibility (Lefley, 2000). The mental health system

continues to strive to create community services for individuals that have serious mental illness with limited success (Sanders, Szymanski, & Fiori, 2014).

Caring for an individual with mental health problems

Nowadays, worldwide, the most important caregivers for people with mental health problems and intellectual disabilities are families (Lefley & Hatfield, 2005). A critical concern that emerges with family caregiving is that at some point in time, parents will get older and their ability to take care of someone else will diminish, leaving care for the family member with a mental disorder to another person, usually the next generation in the family of origin: siblings (Lefley & Hatfield, 2005).

Brothers and sisters are usually considered the first replacement for the roles executed by parents in the care of family members with chronic mental illness (Leith & Stein, 2012), because many people with long-term mental disorders do not have a conjugal or intimate relationship outside of the family. Many studies (Jewell & Stein, 2002; Lefley & Hatfield, 1999, 2000) show that health services and the family itself do not prepare brothers or sisters to realise the role of caregiver later in life (Leith & Stein, 2012).

Many people think about the caregiving of their siblings as something that will happen in the future without making any plans. Because parents take control of everything and don't necessarily talk about this responsibility or the possibility of needing a champion in the future, siblings may be unprepared to assume the role of caregiver for their brother or sister (Lefley & Hatfield, 2005).

Some studies (Lefley & Hatfield, 2005; Sanders et al., 2014) show the importance of the sibling in the future of an individual with chronic mental illness and the necessity to start developing the skills that will help this relationship to succeed early in life. Ways to improve this possibility include workshops by service providers to prepare parents and family members for the transition and to provide the tools for siblings to undertake the task (Lefley & Hatfield, 2005).

In order to provide holistic care to a person with mental health problems, it is necessary to attend to all the needs of the individual and his/her family, including siblings. According to Giallo, Gavidia-Payne, Minett and Kapoor (2012) services need to improve their resources to help brothers and sisters, because these people will be future caregivers. Knowing the sibling and their concerns about the future is key to developing interventions that could change the situation (Giallo, Gavidia-Payne, Minett, & Kapoor, 2012).

The sibling of an individual with mental illness

There is paucity of literature related to siblings, but some noteworthy matters have been already studied, such as the results of peer support programs for siblings of people with a mental illness (Foster, Lewis, & McCloughen, 2014), how people with a sibling with a mental illness perceive mental health services (Lukens et al., 2002) and the impact the brother or sister with the mental illness has on the life of the healthy sibling (Sanders et al., 2014). It is important to understand the relationship between brothers and sisters with a mental illness and their siblings to identify ways

to improve the treatment and care of young people with mental illness and support their siblings.

In a review of a peer support program (Foster et al., 2014) it was discovered that siblings of people with a mental illness experienced many feelings such as guilt, embarrassment and felt moments of stress, burden and stigma in relation to their brother or sister and their mental health condition. To manage these emotions it is necessary to have a support service for siblings. Peer support programs appear to be the optimal choice judging by their good results (Foster et al., 2014). Brothers and sisters commented that participation in the program was positive in their lives, because they learned new skills to deal with their siblings' illness and at the same time they met people in similar situations to them, so they could talk about their experiences and feel that they were not different from other people (Foster et al., 2014).

Not just seeking support for themselves within peer support programs, most siblings want to be part of the treatment and care of their brother or sister, because they feel that it is important to be part of the process and that all family members stay involved (Giallo et al., 2012). Nevertheless, it is not easy to unearth mental health services that work together with consumer and family. Lukens et al., (2002) revealed that mental health services do not usually integrate siblings in treatment and care because they are not the first line carers, so professionals reason that is better to not provide information to siblings and communicate merely with parents (Lukens et al., 2002).

According to Lukens et al (2002), all family members who are involved with the individual with a mental illness have essential knowledge about the person, such as symptoms, behaviours and personal patterns. This knowledge could be of great assistance to the process of treatment and care and it is important to have an exchange of information between the consumer, family members and mental health professionals, working together (Lukens et al., 2002).

Siblings regularly seek information to help themselves to understand what is happening with their brother or sister and also to help their parents and support the family to stay together (Sin, Spain, Jordan, & Griffiths, 2014).

Studies (Giallo et al., 2012; Honey, Alchin, & Hancock, 2014) have shown how important it is to provide support for siblings and to include them as part of the process, because a well sibling is much more helpful inside the family group than a sibling who feels that they don't belong. Many siblings develop or are identified as having the potential risk for developing mental health issues themselves, while trying to cope with the brother's or sister's mental illness. It is important that mental health services recognize the importance of integrating siblings when communicating and interacting with the family (Giallo et al., 2012).

Chapter Summary

This chapter described the literature review about the outcomes of deinstitutionalization, impacts of caring for a person with mental illness and what is known about the experiences of siblings of people with a mental illness. The

following chapter will present the methodology from this study, a qualitative research with semi-structure interviews.

Chapter 3

Methodology

This chapter presents the methodological approach for this study. It discusses the study design, data collection and analysis as well as ethical considerations for the study.

Study Aim

The aim of this study was to examine the experiences of siblings of young people with a mental illness living in Victoria, Australia.

Research Design

A qualitative interpretive approach was used to explore the life experiences of siblings who have a brother or sister with a mental illness. This design is used when the researcher is interested in comprehending the subjective experiences of a person in particular determined circumstances. Specifically, the research design was interpretive phenomenology, which is the study of lived experiences, where the researcher explores the experiences of a particular group of people through interviews or descriptions in a search for meanings for that individual and in that moment (Borbasi & Jackson, 2011).

Qualitative research is an instrument for nurses and midwives when they seek to understand issues related to human life based on individuals' experiences. Through a number of non-statistical methods it is possible to collect data to generate findings. Qualitative research is not concerned with generalizing findings to other situations,

but attempts to examine a situation by itself and draw conclusions according to this experience (Borbasi & Jackson, 2011).

This study utilised semi-structured in-depth individual interviews with siblings of young people with a mental illness. This kind of interview allows the researcher to be flexible when ordering the questions and to respect the time of the interviewee when telling of his/her experience (Barbour, 2008).

An in-depth semi-structured interview provides a certain level of organisation, but enough flexibility to change the course of the interview managing the sequence of questions and giving space for issues as they start to develop during the interview. A good interviewer must be sensitive to cues to know when to ask another question or allow more time for the participant to talk more freely about his/her experiences whilst taking advantage of this to create other questions to explore this moment more deeply (Barbour, 2008).

The researcher is integral to qualitative research because to collect data it is necessary to have strong interviewing skills as well as the capability to read other signals that the participant might send during the interview, such as facial expressions or body language indicating comfort levels and other emotional experiences (Barbour, 2008) .

Following an extensive review of the literature a schedule of indicative questions to guide the interview process was created. Demographic questions such as age and gender were also included.

Participant Recruitment

The population of interest was people with a brother or sister with a mental illness in Victoria, Australia. However, for the purposes of this study the sample was limited to students and staff related to Monash University. Participants were drawn from a purposeful sample of staff and students who were siblings of people with a mental illness.

The participants were recruited through advertisements in Monash Memo, flyers placed across Monash campuses and invitations sent via email to alert members of the Monash community about the study. Participants who responded to the study also referred others through a snowballing technique. The inclusion criteria were people who have a sibling with a mental illness current working or studying at Monash University. The exclusion criteria were people under 18 years of age or/and unable to speak or read English. Six in-depth interviews were conducted.

Data Collection

The interviews were conducted at a meeting room at Monash University or via the telephone at the preference of the interviewee, between May and June 2015. An honours degree student accompanied by one of two academics with a mental health nursing background conducted them. The meeting room was an appropriate environment to conduct the interviews giving privacy to the participants and promoting a comfortable space, free from interruptions. Participants' feedback was sought at the end of each interview.

Interview Questions

The questions were related to the participant's life, living with a brother or sister with a mental illness and their experiences. The questions included the following:

- *Tell me about yourself and your family.*
- *Describe the situation with your brother/sister and their mental health problem.*
- *Tell me about your experience of having a brother or sister with a mental illness.*
- *What is your understanding of your brother or sister's diagnosis?*
- *Tell me what it's like having a brother or sister with a mental illness.*
- *Tell me what impact having a brother or sister with a mental illness has had on you.*
- *What support do you currently receive that helps you to care for your brother or sister?*
- *What positives can you identify during your experience?*
- *Looking into the future, what would you like to see happen for yourself and your brother/sister?*

Data Analysis

At the conclusion of each interview, the researchers discussed the interviews and their overall thoughts and reactions. The audio recordings were sent to a professional transcribing service. All interviews were transcribed verbatim and double-checked for accuracy.

Thematic analysis (Vaismoradi, Turunen, & Bondas, 2013) method was used to analyze the data from the transcripts in this study. First the phase called *familiarizing*

was undertaken where the student researcher read the transcript from the interviews many times, taking notes and trying to understand the main ideas within the phenomenon. After that, the search for themes started. In a brainstorm between the researchers the themes were determined. This was followed by a reviewing of the themes and definitions and names for each theme were created (Vaismoradi et al., 2013).

The final report is a collection of all the findings of the analysis of the interviews according to the themes that emerged.

Ethical considerations

Ethics approval was obtained from Monash University Human Ethics' Committee. This project was submitted to Monash University Human Research Ethics Committee (MUHREC) as a low risk project because it was not expected that participants would experience more than mild discomfort during the interview. If any of the participants felt any discomfort during the interview they had the right to stop participating and could be referred to the Counseling Service that is provided by Monash University to its students and staff members (Monash University, 2014) . Fortunately no participant became distressed.

Participation in the study was voluntary. A participant information sheet was provided to participants and at the beginning of each interview the aim of the study was stated to the participants, the rights of the participants about confidentiality and freedom to remain in the interview as long as they felt comfortable. Permission for audio

recording was also requested at this point. After that the participants were asked to sign a consent form for the research.

The interviews were conducted in English and audio recorded for verbatim data transcription to aid data analysis and guarantee accurate reporting of the interview. The researchers also made their own notes during the interviews.

Participants' confidentiality was respected at all times. The names of the participants were de-identified on the interview transcript and pseudonyms have been used. No form of identity will be used in any future report or publication. Data from the interviews were securely locked and stored in the School of Nursing and Midwifery and will remain there for 5 years. After this period all data will be destroyed.

Chapter Summary

This chapter described the methods used in this study. A qualitative approach was implemented using semi-structured interviews for data collection. The following chapter will present the findings from this study and the discussion comparing the data collected by this study with previous literature will be presented in chapter five.

Chapter 4

Findings

Introduction

This chapter will discuss each of the main themes that emerged from the analysis of the data examining the experiences of young people with a sibling with a mental illness. While all participants' experiences were unique, common themes that were shared by all were located within the narratives. The themes and sub themes are presented in Table 2.

Participants

In total, the researchers conducted six interviews with siblings of people with a mental illness. They were all women with at least one brother or sister with a mental illness, with some cases of two siblings with a mental illness diagnosed within the family. They were aged between 18 and 58 years old. All were working in or studying a health profession. The siblings' diagnoses occurred when the participants were in childhood or adolescence. The diagnoses were multiple varying across depression, anxiety, eating disorder, schizophrenia, borderline personality disorder, autism and behavioral issues.

Themes

Four main themes emerged from the data. The first theme is *Lack of Support* which is represented by all the moments that the siblings felt excluded, sometimes because of non-existence of a service itself; other times because of the incapacity of health professionals to involve the well sibling in the process of treatment and care of his/her

brother or sister and even by other family members who struggled to manage and cope with all the issues that arise with a person with a mental illness.

The second theme is *Tacit approval for inappropriate behaviors*, where it appears there is a tolerance of certain behaviors by the sibling of the person with a mental illness. The third theme is *Being Anxious* where the anxiety of living with a sibling with a mental illness can create anxiety in the well sibling. Finally, *the fabric of the family* explains how the family reacts and adjusts to having a person with a mental illness.

Table 2. Themes and Sub Themes

Themes	Sub Themes
Lack of Support	Lack of Services
	Lack of Information
Tacit approval for inappropriate behaviours	Protection/Advocacy
Being Anxious	Fear of the unknown
	Fear of sibling
	Anxiety in the healthy sibling
The fabric of the Family	Structure and relationships

Lack of Support

From the interviews it was noted that the participants felt a clear lack of support for themselves and for other family members. One participant stated:

“There was not much support at all that we could get for my mum, which was really awful” (P1).

This lack of support devolved into two sub themes: *Lack of services*, where participants reported difficulties in finding professionals and mental health services in general and *lack of information*, where participants reported that, upon finding the appropriate mental health services available, mental health professionals were unable to provide enough useful information to help the family, including referral to non

government agencies. None of the participants was referred to non-government organizations such as ARAFMI or the Mental Illness Fellowship.

Lack of Services

Initially, participants and their families did not know where to go for help and how to access appropriate mental health services. They “shopped around” (Participant 1), talked to their GPs, or sought private psychological help. When they finally contacted public mental health services many access points referred them on to another parts of the service. This resulted in multiple phone call, and the telling and re-telling of their stories. The families are often left without any help as captured in the words of participant 1:

“Maybe it was someone saying the best you can actually do right now is to get counselling for yourself and for your daughters and your husband and then you'll be able to better support him. Even that at the time would've been so helpful, whereas all we got was just like a door slammed in my mum's face over and over”.

The participants noted that there is a gap in service delivery especially in terms of providing a continuous service for their siblings. There is a lot of emphasis on managing the acute symptoms of people with mental illness by mental health services. On the other hand, there are very few services available for the everyday issues that impact on the lives of the young person with a mental illness as well as their families. None of the participants in this study mentioned non-government organisations such as SANE Australia or ARAFMI as a source of help.

Participant 3's sibling was diagnosed many years ago and she reveals how in the past mental illness was taboo. She couldn't find, and doesn't even remember the existence of any support.

“Not that I know of. I don't - things were very different then. Mental illness was something you didn't talk about and I don't recall any support being offered anywhere”.

Lack of Information

The participants reported the lack of information about the illness, the diagnosis and treatment as something really important to the way that they dealt with the sibling with a mental illness, because not knowing what is going on makes everyone a “bit blind”, like participant 1 stated:

“You're trying to be there to support everybody and I'm trying to support my mum as well and support my dad and we're all trying to support each other and nobody knows what anyone's doing. It was all the blind leading the blind and I felt just completely hopeless and helpless”

Participant 2 said that she just wanted some kind of explanation about “...*what my brother was going through, because I didn't quite understand why is he like he is*”.

This understanding would go a long way to make things easier to comprehend.

Participants stated that whilst parents were provided with information, albeit scant and often provided at a time of distress, where it was poorly comprehended, siblings were left out of the conversation. Health professionals privileged the privacy of the person with the mental illness over the needs of their sibling and at times even parents. One participant noted that as the person was an adult they were not “entitled to information” (participant 2). Another stated that she felt “locked out” (participant 6).

Even when families were offered family therapy, it was generally only provided to the parents and the young person with the mental health problem and not the other siblings. Participants would have liked to have had the opportunity to talk with a

young person who was also a sibling of a person with a mental illness as a “peer support or mentor” (participant 1).

The information these participants needed should have been provided by mental health professionals or be offered somewhere accessible to the family and friends and to people with a mental illness themselves. Despite a number of organisations available to assist families, the participants themselves did not know about them and were not referred or provided with information about them by the health services.

Tacit approval for inappropriate behaviours

The participants showed that being a sibling of a person with a mental illness can often lead to passively becoming accomplices in inappropriate, wrong or dangerous behaviours. Since their siblings are loved ones, the participants care and worry about them, and want to make them feel comfortable. Sometimes their siblings’ behaviour caused fear, other times there was an absolute lack of information on how to manage unexpected behaviours. Immaturity and fear of causing distress also played a part in the way the situation was often dealt with.

In such situations the participants have little option but to assume a position of concession, and that leads to them accepting behaviours that would otherwise not be tolerated:

“The problem for me was that she used to tell me when she was about to try another suicide attempt and tell me not to tell anyone. I was - then I was 14 and I was quite worried, what do I do? I can't tell because she told me not to because she's my big sister but then I'd think well I don't want her to try and kill herself”. (Par 3)

In the above statement, participant 3 is faced with her older sister with a mental illness demanding her cooperation in hiding a suicide attempt. Seen out of context, this is something that would easily be marked as demanding urgent report, but the participant's sister was older, and therefore carried a certain authority with that. The participant was 14 years old and at that age it is hard to properly weigh authority and responsibility. While just ignoring the facts would hardly produce a positive result, there was just nothing else that seemed a reasonable alternative.

We can see another example of this kind of approval when participant 4 tells how she accepted disturbing and potentially harmful behaviour by her brother:

“When he was aggressive, he was throwing things at me like knives and things and I was hiding in my room, shutting - holding my bedroom door shut. This is while I was babysitting him and he'd have the knife under the door to try to, like, cut my face and things like that. Luckily I was older and bigger and I never had any injuries, but it was very frightening”.

No attempt was made to change that behaviour; all she could do was to hide and shelter herself, she didn't spoke with her parents at that time because she felt the responsibility was hers.

Protection/Advocacy

The participants exposed a tendency to conclude that, as many everyday situations were more difficult for the sibling with a mental illness than for mentally healthy people, their siblings were entitled to not have as much demanded from them. This sentiment ends up leading the participants to take a position and defend their siblings when third parties, usually the parents, undertook a more authoritarian or expectant approach. As we can see in this quote from participant 1:

“Like, it's hard enough for him to get up in the morning and get on with his day with being a prisoner in his own mind and having such severe depression and anxiety that I just think that's enough, that's enough. He doesn't need all

this other stuff. Sometimes I have to say that to my mum and say he's doing his best, he really is”.

Here, participant 1 shows that behaviour clearly. She thinks that it is too hard for her brother to manage his daily life with his mental illness, and therefore her parents shouldn't be so hard with him as they would be if he was mentally healthy and exhibiting the same behaviour. Demanding his compliance with small issues such as the time to get out of bed especially given his difficulty sleeping in the first place seems to participant 1 as incompatible. She makes it clear that she will tell that to her mother, defending her brother, excusing and justifying his behaviour.

Adopting a similar approach, participant 2 clearly says she defended her brother against the way their parents treated him:

“Sometimes I'd find that the way he got addressed by my parents was a bit...[The participant didn't complete the sentence.] I wouldn't want to be addressed that way, so I kind of defended him in that way”.

Participant 4 discussed how difficult it is for the family to know how much they need to push the sibling with a mental illness, because sometimes an excess of care, though inevitable, can be detrimental to the future of the person. In her words:

“So it was all very well to say that we should have been more hands off, but we found it really impossible to be, in practise, how we would have managed that. Even looking back, it's hard to say that we would have done it differently”.

It is always hard for siblings to know how much they need to protect the sibling with a mental illness or when they went too far advocating for the brother or sister as we can see in the words of the participants. For participant 4, she discovered years later that she went too far in taking care of her brother and developed something called “parentisation”. That is when a brother or sister assumes the parental responsibilities

of the sibling. This feature was found only with participant 4, but was so strong that it was decided it deserved a comment inside the theme of protection/advocacy. It allows an important insight into the possible more extreme dynamics that can be formed in a family that has a sibling with a mental illness and in which the other sibling takes the defensive position very seriously.

After her parents decided to have a more hands-off, liberal instance with the brother, participant four ended up taking the role of the parent in the sense of controlling and caring for her brother in order to leave him clear of risk, which she instinctively perceived as lacking in her parents' approach.

"I took on a lot of the responsibility of managing my brother's behaviour".
(Participant 4)

In the following quote, participant 4 tells how her parents had already surrendered the responsibility of their son's wellbeing to her when he presented a risk to himself. That responsibility fell upon participant 4 as she stated in her words:

"I think they thought that was the right approach, that if my brother... so for example, if my brother was running, we'd be all walking down the street and he'd be running ahead and my parents would let him run and I would go and grab him before he ran onto the road".

Participant 4 also says that the process ended up being natural and instinctive, and hints that her parenting instance ended up filling up the void left by her parents' hands off approach:

"I had my instincts as well as a protective older sibling to care for him and no one ever thought about my role in this. My role actually impacted my parents' ability to parent him as well, because I was so proactive about it that, you know, my instincts, I guess, were kind of - were different to my parents and how to manage that".

Participants generally were tolerant, apologetic and held no resentment for their sibling.

Being Anxious

Quite a predictable outcome for the participants was a strong tendency to develop anxiety and stress. Dealing with and taking care of a constantly mentally ill person is, by itself, a very demanding task, and given the problems discussed in the other themes, this issue can be potentially increased. The theme of being anxious can be broken down into the following sub themes: fear of the unknown, fear of the sibling and anxiety in the healthy sibling.

Fear of the unknown

The participants showed that a recurring anxiety they faced was constantly dealing with the fact they didn't know exactly what to expect from their siblings. As participant 1 says:

“I always think, unlike with a physical illness, when you know when things are getting worse and you possibly have more of an idea when the end is coming, I had no idea. We had no idea what was a bad day for him and what was a good day, and when things were worse and when things were better and when the end might come or even if that was a possibility”.

This is complemented by participant 4:

“It's still really hard. It's something I haven't felt comfortable telling a lot of people about. Very few people know, particularly because it's been this sort of insidious situation, like he left at the time and seemed something just acute, but then it gradually became a long, ongoing issue and it's hard”.

This shows that the consequences of the mental illness of her brother became a continuous source of distress for her. To this day she feels uncomfortable with that and prefers not disclosing to many people.

According to the participants mentally ill people tend to be unpredictable and this in turn leaves their siblings to constantly wonder whether some sudden crisis will strike, or whether they'll know how to cope with the crisis. This constant worry becomes anxiety, and haunts the participants.

Fear of the unknown also arose for the siblings regarding their own mental health and they were concerned they would develop a mental illness themselves or that their children might develop a mental illness. Participant 3 stated that she was frequently thinking, "Is this depression or is this my teenage son"

Fear of the sibling

Earlier, a quote from participant 4 showed that situations could arise in which the mentally ill sibling will become violent (the incident with a knife in this particular case). These situations are obviously distressing and will certainly cause anxiety, especially if they become regular events and inadequately managed by parents. Participant 3 talks about the same feeling of being afraid of her sibling, also adding a bit of the fear of the unknown:

"But that was how she was, she was scary. She was great fun but she was scary and you always felt like - I don't want to upset her because she'll hit me".

This quote shows that the participants were quite disoriented regarding what to expect from their siblings specifically regarding possible physical assaults. Both fears sub themes: fear of the unknown and fear of the sibling, show that a recurring issue for the participants is how to determine what is part of their sibling's personality, what is caused by the illness, and how to deal with each one of those things.

Anxiety within the healthy sibling

Most of the participants in this study stated that they experienced anxiety and the emotional and behavioural consequences of that. Living with a person with a brother or sister with a mental illness can create anxiety in the healthy sibling as demonstrated by the words of participant 6 who worries about becoming mentally ill too. She lives with a lot of anxiety of discovering a mental illness in herself. This also relates to fear of the unknown.

“Sometimes I think, because it’s happened to two of my siblings, ahhh is it going to happen to me in the future? Humm... maybe knowing... like... say if these symptoms come up you should seek help cause maybe is hereditary”.

A consequence of the development of unrelenting stress in the healthy siblings is that they can develop mental illnesses themselves as stated by participant 1:

“I already am quite prone, I suppose, to getting a bit anxious myself and I just - it was awful. Any time my phone would ring I would start sweating and just - I would be so worried they were going to say the worst [about her brother]”,

She even developed an eating issue.

“I lost a lot of weight, which wasn't good either because I - I couldn't eat because I was so anxious and nervous all the time”.

Though much of their experience occurred in the past, participant 4 now says that it has impacted on her life and personality; she’s now more risk-conscious and worries more about other people than if she hadn’t her lived her youth taking care of her sibling. According to her,

“I can still see that with my friendships now; I'm the one that's sort of risk averse and worried about things that will happen to them as well”.

The fabric of the Family

Having a person with a mental illness in the family can produce different results in the family structure and relationships. Sometimes the family became closer through enduring the many situations and through supporting each other. As participant 1 says:

“it did bring all of us closer together and it brought us together in a whole new way where we were all very raw with each other”

Sometimes the family needed external support to understand and cope with the situation, as stated about family therapy in the words of participant 2:

“The [family] therapy was incredibly powerful on a lot of levels and therapy just taught me to understand my mum and have some empathy for her, that these were the ways that she was trying to cope with her world”.

It should be noted that family therapy was not provided to all participants.

Participants noted that at times their parents didn't know how to deal with a situation and this can be seen in this quote from participant 3:

“I feel very sad for my parents because it would have been extraordinarily traumatic for them. They had no idea how to cope with it, how to deal with it. They were...very little support”.

However, not all families were drawn closer. For participant 2, her brother is estranged from the family completely, her mother is highly anxious and her father depressed with alcohol problems. She herself feels saddened by the outcome and states that she *“feels likes an only child now”*.

Participant 5 was one of a very large family. She not only had two siblings with mental health problems but her parents were both diagnosed with Asperger's Syndrome. As soon as she was able she moved out of home and moved in with an older sibling. The family is fragmented, scattered and have few interactions.

Chapter Summary

This chapter has presented findings from in-depth interviews with six siblings of young people with a mental illness. The interviews explored their experiences of living with a brother or sister with a mental illness. Several themes and subthemes emerged from the interviews, which include: Lack of support, tacit approval for inappropriate behaviours, being anxious and the fabric of the family. Subthemes such as lack of services, lack of information, protection and advocacy as well as fear of the unknown, fear of siblings and anxiety also emerged.

The last chapter of this thesis (Chapter 5) provides a discussion of the major study findings and refers to the extant literature, considers both the study's strengths and limitations, makes recommendations, and suggests implications for clinical practice and further research.

Chapter 5

Discussion, Conclusion and Recommendations

The aim of this study was to explore the experiences of siblings of persons with a mental illness. In total six in-depth interviews were conducted and the narrative data from the interviews were explored using thematic analysis and were explicated in the previous chapter.

Specifically the study aimed to answer these four questions:

- What are the experiences of young people as they discover their brother or sister has a mental illness?
- What are the experiences of siblings as they engage mental health services?
- What impact does having a brother or sister with a mental illness have on the person?
- How can the brother or sister of a sibling with a mental illness be empowered whilst caring for their sibling?

This chapter will discuss the findings with reference to the literature, draw conclusions and implications for practice and offer suggestions for practice and research. The limitations of the study will also be discussed.

What are the experiences of young people as they discover their brother or sister has a mental illness?

Participants in this study lived with increasing uncertainty regarding their siblings' mental state and their often unusual or unacceptable behaviours. They watched as their parents sought help with little success. Once help was at hand they felt some relief but also felt anxious. This study found that siblings of people with a mental illness also experience many other different feelings such as love and affection for the brother or sister, responsibility for helping the family to cope with the new situation and anxiety for being left out of the treatment or because the behaviours of the mentally ill sibling. This result is consistent with what is reported in the literature (Sin et al., 2014). Siblings regularly seek information to help themselves to understand what is happening with their brother or sister and also to help their parents and support the family to stay together (Sin et al., 2014).

What are the experiences of siblings as they engage mental health services?

Siblings of young people with a mental illness in this current study noted the assistance provided by mental health services was not adequate to meet their needs. Generally families found it hard to access services and were referred to multiple agencies before finally locating the correct service. Once in the service, siblings were often omitted from discussion and were provided limited information. This was because at times mental health professionals do not pay enough attention to the brother or sister of the person with a mental illness or they simply do not appreciate the need to help brothers or sisters and are therefore left out of support. Understandably, there is usually a focus on person experiencing the mental illness, however, others such as the siblings are overlooked and forgotten as integral to the treatment plan and in some cases even family therapy. This outcome was also seen in the literature. Lukens et al., (2002) note that frustration with mental health services was a clear and constant message by families in relation to their struggles to even to

connect with appropriate service and mental health professionals. To receive support along with the treatment of the sibling with a mental illness is essential to the healthy sibling.

What impact does having a brother or sister with a mental illness have on the person?

Having a brother or sister with a mental illness can impact a sibling in a number of ways. As a result of being placed in a parental or advocacy role, there are positive consequences such as making the siblings stronger and more mature due to dealing with a number of life stressors at a young age and creating a more inquisitive and assertive brother or sister when dealing with the mental health services and professionals. The negative consequences include the healthy sibling becoming anxious, withdrawn and introverted where they are careful not cause any worries for the family creating his or her role within the family as flexible and adaptable. Without exception the participants in this study experiences their own levels of anxiety and all tended to be cautious. All were in, or studying, health related professions. Nevertheless, all were without resentment of their sibling and continued to advocate and protect. Some participants had less positive comments about their parents and their ability and ways of coping and these consequences have also been noted by others. (Ewertzon, Cronqvist, Lutzen, & Andershed, 2012) claim that siblings experience an ongoing battle in relation to their personal and professional lives as well as with their siblings with mental health problems, their parents, and the mental health system and professionals.

How can the brother or sister of a sibling with a mental illness be empowered whilst caring for their sibling?

Finally for question 4 we established the importance of providing tools for siblings so they can better support their brothers and sisters with a mental illness as well as assisting themselves and one of the best tools is information. This includes information about the mental illness and the associated behaviours that are interconnected with the illness, information about mental health services and measures they can take to increase their own resilience and coping ability. Peer support programs were mentioned by some participants. According to Giallo, Gavidia-Payne, Minett and Kapoor (2012) mental health services must increase their resources to assist siblings because they will likely be future caregivers. Knowing siblings' concerns about the future is vital in developing interventions that could transform the problems (Giallo et al., 2012).

(Foster et al., 2014) found in their research about peer support for siblings of people with a mental illness, that siblings reported that improved awareness of mental illness had enabled and empowered them. They were taught problem-solving skills that were useful both in the home and elsewhere, Moreover, the siblings enjoyed the learning program and that many of the skills learned were applicable in many settings.

Conclusions and Recommendations

Drawing on the aforementioned results, some conclusions can be made. First, knowledge about mental health services is limited in the general population and access to appropriate mental health services is not clear and straight-forward. Well-defined referral pathways are needed. Second, siblings love and protect their brothers and sisters despite inappropriate and even frightening behaviours. They are excused and silently encouraged. Third, siblings suffer their own anxieties and these are

related to developing a mental illness themselves and what the future will be for them, their parents and their siblings. They also worry about passing the potential for mental illness to their offspring. Last, siblings need help.

Governments need to continue to invest in services for young people with a mental health problem and their families and to ensure these services are more visible and are easy to access. Mental health care needs to be a continuous process where consumers and families, and in particular siblings, always have some type of support when they request it, not merely during times of crisis.

Another essential advance to be made relates to the education and training of mental health professionals in order for them to provide enhanced assistance to families; integrating consumers and their families within the process of treatment and care; effectively communicating with them about all aspects and supplying them with adequate information and support.

Specific programs need to be implemented for the siblings of people with a mental health problem that focus on their needs, help them develop improved coping mechanisms and resilience as protection for anxiety and other emotional sequelae in addition to those provided by non-government agencies such as ARAFMI or COPMIA. Peer support programs with suitable backup from mental health professionals would be helpful in achieving these outcomes.

We recommended that further research regarding siblings of people with a mental illness continue to be undertaken to explore in greater depth, their knowledge and understanding, their self-efficacy in managing their brother or sister and themselves,

any state-trait anxiety measures and intervention studies related to specific programs designed for siblings.

Study Limitations

This study had some limitations. Like any study its findings are limited by the characteristics of the sample of analysis, in this case, a small sample of people recruited from within a single University. As with many qualitative projects, caution should be exercised in generalizing the findings. Nevertheless, readers of this account may find resonance with their own experiences.

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