

THE ROLE OF SOCIAL NETWORKS AND SOCIAL SUPPORT ON MENTAL HEALTH SERVICE UTILISATION BY MENTAL HEALTH CONSUMERS IN RURAL NEW SOUTH WALES

by

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Exact wording of the title of the dissertation or thesis as appearing on the copies submitted for examination:

The role of social networks and social support on mental health service utilisation by mental health consumers in rural New South Wales.

I declare that the above dissertation/thesis is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

SIGNATURE

DATE

DEDICATION

This work is dedicated to my daughter Eliana Joy Gaga who was born during this project. She is my little rosebud who went to heaven to bloom.

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ABSTRACT

This study employed a generic qualitative design that was descriptive and explorative in nature to discover the role of social networks and social support on mental health consumers' use of mental health services in rural New South Wales. Purposive and convenience sampling was used in order to identify study participants who were mentally stable and who had resided in a rural area for longer than 6 months. Data was collected through semi-structured individual interviews that were audio-recorded and transcribed verbatim. Data was analysed using open coding and thematic analysis and themes, categories and sub-categories were identified. The four main themes were relationships, living with mental illness, social support, and social networks. The findings indicate that the social networks of mental health consumers consisted mostly of family, friends and mental health professionals who were also responsible for providing social support. Recommendations for mental health services and mental health professionals are also discussed.

KEYWORDS: severe mental illness, social support, social networks, mental health consumers, mental health professionals, mental health services, stigma, rural communities, family, friends.

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CHAPTER 1

ORIENTATION TO THE STUDY

*“Not sure if I’m doing this right as a novice researcher but
I want the voices of mental health consumers to be heard...”
(extract from reflective journal: 19/05/2015)*

1.1 INTRODUCTION

Mental and substance use disorders have been identified as the leading cause of global non-fatal burden of disease and are responsible for 7.4% of the burden of disease worldwide (Ferrari, Norman, Freedman, Baxter, Pirkis, Harris, Page, Carnahan, Degenhardt & Whiteford 2014:1; Whiteford, Degenhardt, Rehm, Baxter, Ferrari, Erskine, Charlson, Norman, Flaxman, Johns, Burstein, Murray & Vos 2013:1579). Mood and anxiety disorders are the most prevalent in the general population globally (Baxter, Scott, Ferrari, Norman, Vos & Whiteford 2014:507; Kessler, Anguilar-Gaxiola, Alonso, Chatterji, Lee, Ormel, Üstün & Wang 2009:4; Sansone & Sansone 2010:18). The global prevalence of anxiety disorders is 4% while the global prevalence of major depressive disorders is 8% (Baxter et al 2014:509). Although schizophrenia has a very low prevalence in the general population, it has been found to be the most disabling mental disorder (Whiteford et al 2013:1582).

Edmondson, Pahwa, Lee, Hoe and Brekke (2012:110) conducted a study among individuals living with schizophrenia and found that as social functioning improved, their satisfaction with their social relationships did not. These authors conclude that interventions intended to improve social functioning among individuals living with severe mental illnesses such as schizophrenia should consider the complex nature of their social relationships.

Living with severe mental illness has been found to have profound consequences on social networks, relationships and social interactions. Those living with severe mental illness may also experience stigma, rejection and social isolation from others, leading them to feel the need to conceal their diagnosis of severe mental illness from others (Perry 2014:33; Ye, Chen, Paul, McMahon, Shankar, Rosen & O’Reilly 2016:532).

1.2 BACKGROUND

One in five Australians (20%) aged between 16 and 85 years report having experienced a mental disorder in the previous 12 months, with over seven million (45.5%) confirming having had a mental disorder during the course of their lifetime (Australian Institute of Health and Welfare 2015:1; McEvoy, Grove & Slade 2011:957; Slade, Johnston, Teesson, Whiteford, Burgess, Pirkis & Saw 2009:12). Anxiety disorders and affective disorders are the most common among adults each year (Australian Institute of Health and Welfare 2015:1; Commonwealth of Australia 2009:16-17; McEvoy et al 2011:957). These are collectively known as 'high prevalence' illnesses. 'Low prevalence' mental illnesses, such as schizophrenia, affect 1% to 2% of the adult population. Furthermore, 3% of Australian adults suffer from severe mental illness. Severe mental illness is based on the diagnosis, severity of symptoms, duration of illness or chronicity, and disability caused. This represents approximately half a million Australians of which fifty percent (50%) have schizophrenia and other psychoses. The rest are comprised of severe depression and anxiety disorders (Australian Institute of Health and Welfare 2015:2; Commonwealth of Australia 2009:16-17; Morgan, Waterreus, Jablensky, Mackinnon, McGrath, Carr, Bush, Castle, Cohen, Harvey, Galletly, Stain, Neil, McGorry, Hocking, Shah & Saw 2012:735). Twenty-four percent (24%) of the burden of non-fatal disease in Australia is as a result of mental illnesses, therefore, the impact of mental illness cannot be ignored (Australian Institute of Health and Welfare 2015:2; Commonwealth of Australia 2009:17). The 2007 National Survey of Mental Health and Wellbeing records that 34.9% of Australians who had suffered a mental illness confirmed that they had utilised mental health services in the preceding 12 months. The remaining 65.1% chose not to utilise mental health services although they were living with a mental illness (Jorm 2014:795; Slade et al 2009:15).

Kelly, Stain, Coleman, Perkins, Fragar, Fuller, Lewin, Lyle, Carr, Wilson and Beard (2010:16) and Kelly, Lewin, Stain, Coleman, Fitzgerald, Perkins, Carr, Fuller, Lyle and Bear (2011:1338) conducted a study in rural, remote and regional New South Wales on the mental health and well-being of rural communities. Their findings revealed that the needs of rural communities are different from urban communities as the minority of people with mental health problems tend to seek help for their problems. This could be as a result of staff shortages and mental health services being difficult to reach in rural areas. These authors found that there were higher levels of psychological distress in

rural communities. These findings are consistent with the results of Baxter et al (2014:511) and Slade, Grove and Burgess (2011:312), who found that psychological distress increased over time, especially in rural communities. The authors pose a question as to what mediates the effect of the psychological distress on an individual in a rural community.

Social support would, therefore, be critical in a rural context as rural communities tend to be more isolated when compared to urban communities (Kelly et al 2010:16). Although rural communities are more isolated than urban communities, Collins, Ward, Snow, Kippen and Judd (2016:1) propose that connectedness may be the underlying mechanism which influences the mental health and well-being of rural communities. Social networks and social support have been found to improve mental distress in those living in rural communities (Beaudoin, Wendel & Drake 2014:336).

Derosé and Varda (2009:2272) conducted a systematic review on social capital and health care utilisation and found that there is a growing interest and trend as to how broad-level community characteristics, such as social capital and social networks, influence the utilisation of health services. Social support is the perception of the individual that those in their social network care about their welfare. As such, social support is more subjective and less quantifiable than social networks (Maulik, Eaton & Bradshaw 2011:30). On the other hand, social networks have been described as the number of social contacts that one has and the frequency of interaction that one has with them. Therefore, social networks are objective and can be quantified. It is through these social contacts (friends or relatives) that a person can receive the assistance they need in a crisis situation (Maulik et al 2011:30).

Thoits (2011a:4) found that social support will generally decrease a person's mental health service utilisation if their condition is not serious, but that when a person has a severe mental illness having social support made their use of mental health services likely, through the use of coercion. This is because friends or relatives would often contact the ambulance who will take their friend or relative who is mentally unwell to the hospital. Thoits (2011a:4) also found that those who had greater social support perceived that they needed treatment less because they felt that the support they had from their social networks (family or friends) was adequate and thus delayed treatment seeking and contact with mental health services. This suggests that social networks and

social supports may sometimes substitute for more formal forms of support. Chang, Chen and Alegría (2014:1-2) investigated the role of social support among different race groups (Caucasian, African, Asian and Hispanic) and found that when it came to accessing mental health services, social networks would often substitute for more formal forms of support, that is, mental health services.

In contrast, Maulik, Eaton and Bradshaw (2009:1223) found that frequent contact with one's social network and higher levels of social support were associated with a greater use of general medical services or general mental health services but fewer specialised psychiatric services. This could be due to the fact that social networks may be able to assist with support, such as making appointments and providing transport to these appointments.

A review of the literature by the researcher revealed that no previous studies investigating the role that social networks and social support play on mental health service use had been conducted in rural New South Wales. The researcher was also unable to locate any studies conducted in any other areas of New South Wales. The majority of the studies the researcher was able to locate were conducted in the United States of America (USA). The researcher also engaged the services of the subject librarian and supervisor who encountered the same lack of relevant literature. The researcher completed searches using the following databases: Ebsco Host, Pubmed, Medline, Science Direct, Google Scholar, Sage, CINAHL and Proquest. Some of the keywords used included: "social networks", "social support", "social support and mental health services", "social networks and mental health services", "social support and mental illness", "social networks and mental illness", "mental illness and interpersonal relationships", "stigma and interpersonal relationships", "mental illness and stigma", "mental health consumer", "mental health consumer and mental health services", "mental health services in rural areas", "mental health consumer and social networks", and "rural mental health consumer". The searches identified some articles however, these articles were either irrelevant, outdated, or both. Examples include studies by Behnia (2004:6); Berkman, Glass, Brissette and Seeman (2000:843); Lam and Rosenheck (1999:13); Nyamathi, Leake, Keenan and Gelberg (2000:318) and Sapra, Crawford, Rudolf, Jones, Benjamin and Fuller (2013:476).

Recent studies that have investigated the role of social networks and social support on mental health service use have employed quantitative methods (Chang et al 2014:1; Maulik et al 2011:29; Thoits 2011a:4). This study aimed to use a qualitative approach to understand the experience of mental health consumers with regards to their social networks and social support and the influence these have on their mental health service utilisation. Yeung, Irvine, Ng, and Tsang (2013:486) conducted a qualitative inquiry into the lived experience of the Chinese and their careers in the United Kingdom with regards to their help-seeking journey of accessing mental health services. The study demonstrated the value that a qualitative approach can add in terms of understanding the lived experiences of those affected by mental illness and the role that social networks and social support play as a part of this.

1.3 STATEMENT OF THE RESEARCH PROBLEM

The disparity between the number of people estimated to be living with mental disorders and the proportion of those who receive adequate and appropriate treatment for these disorders, is known as the 'treatment gap' (De Silva, Lee, Fuhr, Rathod, Chisholm, Schellenberg & Patel 2014:341; Jorm 2014:795).

Lora, Kohn, Levav, McBain, Morris and Saxenae (2012:47) found that the median treatment gap for those living with severe mental illness such as schizophrenia was 69% when high, middle and low-income countries were compared globally. Eighty percent (80%) of those living with severe mental illnesses such as schizophrenia were treated in outpatient facilities in the community which bore most of the burden of care. In Australia 41% of those living with affective (mood) disorders and 62% of people living with anxiety disorders reported not accessing treatment in the preceding 12 months (Jorm 2014:795). Mackenzie, Erickson, Deane and Wright (2014:99) found that although rates of seeking treatment for mental health problems are increasing, the majority of individuals with mental health problems remain untreated.

The 1950's and 1960's saw a worldwide trend of moving patients with severe mental illnesses from hospital settings to less restrictive community settings and placing these patients into the care of family members. This was referred to as 'deinstitutionalisation' (Boschma 2011:224; Hudson 2016:135). Australia was no different. However, the move from institutions to community settings happened before sufficient community-based

mental health teams and support had been established (Pols & Oak 2011:4; Rosen, O'Halloran & Mezzina 2012:390). The researcher wondered how social support or the lack thereof influences the treatment gap. Rebello, Marques, Gureje and Pike (2014:308) propose that having social support may be one of the innovative strategies required in order to bridge the treatment gap for those living with mental illness.

There is a widespread shortage of mental health professionals especially for the care of those living with severe mental illness. These shortages are further aggravated by the maldistribution of mental health professionals, particularly in rural areas (Becker & Kleinman 2013:67; Olfson 2016:983; Thomas, MacDowell & Glasser 2012:1). There is a scarcity of mental health services in rural areas (Thomas et al 2012:1). The shortage of mental health professionals and lack of mental health service have led to an increased burden of care on families (Valentini, Ruppert, Magez, Stegbauer, Bramesfeld & Goetz 2016:1).

The shortage of health professionals in rural areas, along with the deinstitutionalisation, has contributed to the treatment gap. This has placed an increased burden on families to care for family members living with severe mental illness who were once cared for in hospital, and to provide them with social support and care (Bland & Foster 2012:519; Weimand, Hedelin, Hall-Lord & Sällström 2011:703). Pirkis, Hardy, Burgess, Harris, Slade, and Johnston (2010:929) found that 15% of the Australian population cared for a relative with a mental illness and that most of these carers were women. It is in this context of deinstitutionalisation that community-managed organisations were birthed in order to assist those living with mental illness in the community.

Non-governmental (NGO) or community-managed organisations (CMO's) are not for profit organisations that aim to provide comprehensive care to individuals living with mental illness, including supported employment, education, family and carer support, rehabilitation, social inclusion, recovery and relapse prevention (Pols & Oak 2011:5). Thus, community-managed organisations form an important part of mental health consumers' social networks and support.

When people with mental illness engage with community-managed organisations they seem to have improved health outcomes. By engaging in rehabilitation and support services, people with mental illness stay out of hospital and remain well for longer

periods of time (Bateman & Smith 2011:65; Bateman, Rosen, Smith & Hughes 2010:19). The 'revolving door syndrome' is defined as the cyclical pattern of readmissions in acute in-patient mental health units by those living with chronic and severe mental illness (Garrido & Saraiva 2011:1114). Garrido and Saraiva (2011:1114) and McConnell and Perry (2016:119) found that the lack of social networks and social support were a strong predictor for the 'revolving door syndrome'.

A consequence of deinstitutionalisation means that community-managed organisations, along with relatives of those living with severe mental illness, form part of the social networks and provide social support to mental health consumers. Social networks and social support are therefore critical in bridging the treatment gap and halting the revolving door syndrome. Studies have shown that social networks and social support form part of the societal factors that affect the use of mental health services (Chang et al 2014:1; Maulik et al 2011:29; Maulik et al 2009:1223; Thoits 2011a:4).

With this in mind, the researcher wanted to discover what social networks and social support mental health consumers have. The researcher sought to examine how having contact with social networks and having social support affects mental health service utilisation by mental health consumers. The researcher was also interested in what social networks and support exist and how their role can be enhanced.

1.4 RESEARCH AIM

The aim of this study is to enhance the understanding of the role that social networks and social support have on mental health service utilisation by mental health consumers in rural New South Wales. The knowledge gained from the study will improve service delivery, bridge the treatment gap and mitigate the effects of the revolving door syndrome.

1.5 RESEARCH OBJECTIVES

The research objectives were:

- To establish what social networks mental health consumers utilise.

- To explore and describe the perceived support that social networks provide to mental health consumers.
- To explore and describe the influence of social networks in the decision-making process to utilise mental health services.
- To make recommendations for health care workers to enhance the role of social networks in the utilisation of mental health service.

1.6 RESEARCH QUESTIONS

The research questions were:

- What kind of social networks are predominantly used by mental health consumers?
- How are social networks perceived as supportive measures by mental health consumers?
- How do social networks affect the use of mental health services by mental health consumers?
- What is the role of social networks in mental health service utilisation?
- What can be done to enhance the role of social networks?

1.7 DEFINITIONS OF KEY CONCEPTS

1.7.1 Mental illness

This is the psychological state or disease of the mind of someone who has emotional or behavioural problems that are severe enough to require psychiatric intervention (Princeton University 2016). In this study, mental illness will refer to mental health consumers who have been diagnosed by a psychiatrist with a disease of the mind and may require psychiatric intervention with the use of medication to remain mentally

stable. This includes diagnoses such as severe depression, bipolar affective disorder, schizophrenia, schizoaffective disorder and bipolar affective disorder. This study will focus on severe mental illness.

1.7.2 Severe mental illness

This is a mental illness that causes disability to the degree that it influences daily life (Arvidsson 2010:427). In this study, severe mental illness refers to those persons who are living with a mental illness that is chronic in nature and causing significant disability in their everyday lives. The participants in this study were living with severe depression, bipolar affective disorder, schizophrenia, schizoaffective disorder, and bipolar affective disorder.

1.7.3 Mentally stable

This can refer to no readmissions to mental health facilities, no adjustment of medication in the previous 12 months due to an increase in symptoms, and the absence of psychotic symptoms in the past 6 months (Depla, de Graaf & Heeren 2005:126). In this study, participants were deemed to be mentally stable if they were not readmitted to hospital or had their medication adjusted in the previous 12 months, or experienced any psychotic symptoms for the past 6 months. This formed part of the inclusion criteria of the study.

1.7.4 Mental health consumer

This refers to a person with a diagnosis of a mental illness who accesses or has accessed mental health services (Department of Human Services Victoria 2009:2). In this study, mental health consumers referred to those who had been diagnosed with severe mental illness who used community mental health services and acute in-patient services on an ongoing basis in the Northern Region of New South Wales.

1.7.5 Social support

Social support relates to the assistance that one can receive from others, such as family and friends. It is also one's perception that they are loved and cared for and that there

are people to turn to in times of need or crisis. Social support may consist of emotional (intangible) or instrumental (tangible) support. Emotional support refers to having people that you are able to talk to while instrumental support refers to tangible support such as help with transport, house-keeping or money (University of Minnesota 2016). In this study, social support applies to the perceived support that mental health consumers feel they receive from their social networks. This includes emotional and instrumental support.

1.7.6 Social network

“A network of social interactions and personal relationships” (*Oxford Dictionary* 2016, “social network”). Social networks are also the number of social contacts that one has and the frequency of interaction that one has with them (Maulik et al 2011:30). In this study, social networks will refer to the number of social contacts or interactions a person has. In other words, whoever forms part of the mental consumer’s world. This includes family, friends, relatives and non-governmental organisations.

1.7.7 Mental health services

Mental health services are health services that specifically attend to the needs of those experiencing a mental health crisis or mental health issues (Horspool, Drabble & O’Cathain 2016:2). In this study, mental health services will refer to those services that provide a specialised service to people living with severe mental illness. This includes both acute services (emergency department and acute mental health in-patient units) and community-based treatment which is offered via community mental health teams that offer psychiatrist consultations and case management.

1.8 RESEARCH DESIGN

The research methodology describes the techniques used to structure a study and to gather and analyse the information in a systematic way. This includes the overall plan for addressing the research question and how to enhance the study’s integrity (Liamputtong 2013:9; Polit & Beck 2012:741). What follows is a discussion of the research approach, research design, research setting, sampling, data collection and data analysis.

1.8.1 Qualitative approach

Qualitative research evolved from behavioural and social sciences as a way to understand the unique, dynamic and holistic nature of humans. Qualitative research is a subjective and systematic approach for describing life experiences and giving them meaning. The philosophical base of qualitative research is interpretative, humanistic and naturalistic. Qualitative researchers hold a belief that truth is complex and dynamic and can only be found by studying people in their natural settings or environments. Qualitative research aims to promote an understanding of human experiences and develop theories that describe these experiences (Borbasi & Jackson 2016:13; Grove, Gray & Burns 2015:20). More detail will be provided in Chapter 3.

Because human responses are difficult to quantify, qualitative research is the most efficient method for investigating emotional responses rather than quantitative research (Grove et al 2015:20). Therefore, in order to fully appreciate the experiences of mental health consumers and the influence that their social networks have on their mental health service utilisation, a qualitative approach was chosen for the study.

1.8.2 Research design

Exploratory, descriptive, qualitative research is a research design that does not subscribe to a particular qualitative research approach. An exploratory, descriptive research design is usually used by researchers when exploring a new topic. Such studies are developed to provide insight into practical problems and are also referred to as basic qualitative research designs or generic qualitative research designs (Creswell 2016:259; Grove et al 2015:76-77; Schneider, Whitehead, LoBiondo-Wood & Haber 2013:105).

This was the research design chosen for the present study as the researcher wanted to explore the role of social networks and social support and describe their influence on mental health service utilisation. The research design is discussed in more detail in Chapter 3, along with the general characteristics of qualitative research.

1.9 RESEARCH METHODOLOGY

The research methodology will include the research setting, population, sample, sample methods, data collection, and data analysis.

1.9.1 Setting and population of the study

The research setting is the location or site where the study will be conducted. There are three common settings where research can be conducted. These are natural, partially controlled, and highly controlled settings. A natural setting is an uncontrolled, real life situation or environment. A partially controlled setting is an environment that is manipulated in some way by the researcher, while a highly controlled setting is an artificially constructed environment for the sole purpose of conducting the research (Burns & Grove 2011:40-41; Grove et al 2015:276-277).

The present study was conducted in the natural setting of the northern region of New South Wales which is also known as the New England North West Regions of New South Wales. The region covers a land area of 98,606 square kilometres with a population of 183 000 (Regional Development Australia 2016). The northern region contains regional, rural and remote towns and communities. Within the northern region there is one acute mental health in-patient unit with a capacity of 25 beds. There is also one voluntary mental health in-patient unit with a capacity of 8 beds. There are three community mental health teams who service the three districts (Peel, Mehi and Tablelands).

A target population comprises of all the cases of interest to the researcher; that is, the group about whom the researcher wants to make generalisations (Grove et al 2015:6; Schneider et al 2013:185). For the present study, the target population included all adults from a rural or regional area of New South Wales who have a diagnosis of a severe mental illness and have accessed mental health services. Since it is not feasible to use the target population, an accessible population was used. An accessible population is the number of cases that meet the selection criteria (Schneider et al 2013:186). The accessible population included the participants who were available and willing to participate after being informed about the study. Chapter 3 will offer further details.

1.9.2 Sample and sample methods

Within qualitative research, non-probability sampling is used where not every element of a population has an opportunity to be selected for a study sample (Grove et al 2015:263).

For the present study, the researcher made use of two forms of non-probability sampling which were purposive sampling and convenience sampling to select research participants. In purposive sampling, the researcher deliberately chooses research participants who are information rich and who will thus yield data that is relevant to the study (Borbasi & Jackson 2016:158; Creswell 2016:110). Convenience sampling uses the most readily accessible and willing persons as study participants (Burns & Grove 2011:305; Schneider et al 2013:189). As such, participants who were willing and available were included in this study. Potential participants for the study responded to flyers (Refer to Annexure A and Chapter 3 for further details) that provided a brief description of the study and contact information of the researcher. Potential participants were also recruited through the assistance of local mental health services.

The sample for the study consisted of adults aged between 18 years and 65 years since they were able to give their own consent. The participants had a confirmed diagnosis by a psychiatrist of a severe mental illness (severe depression, schizophrenia, bipolar affective disorder) as these conditions have been found to be chronic and enduring and may significantly affect a person's ability to function. The participants were mentally stable and not hospitalised in the previous 12 months or had not had their medications adjusted in the previous 6 months. The participants had also resided in a rural or regional area of New South Wales for longer than 6 months so they were familiar with mental health services in their local area and had established some form of social network. This was the inclusion criteria. Chapter 3 discusses sampling in more detail.

1.9.3 Data collection methods

The necessary permissions and informed consent were obtained by the researcher from all stakeholders before data collection commenced (Section 1.8 and 3.7 discuss this further under the heading 'Ethical Considerations').

Data collection is concerned with the identification of research participants and the systematic and precise gathering of information (data) from these participants in order to meet the specific research purpose, objectives or questions (Burns & Grove 2011:535; Grove et al 2015:502).

Data was collected through face-to-face semi-structured interviews in a place the participants felt most comfortable, which was usually their own homes. The interviews were conducted by the researcher and thus the researcher was the primary instrument for data collection (Creswell 2013:45; Hissong, Lape & Bailey 2015:105). The researcher made use of open-ended questions in order to gain a better understanding of mental health consumers' experiences of utilising mental health services and the influence of their social networks and social support. At the start of the interviews, the researcher again provided an explanation of the purpose of the study and a description of how confidentiality and anonymity will be maintained. The informed consent form was reviewed and signed (Refer to Annexure C). The participants were provided with information about their voluntary participation and their right to withdraw from the study at any point during the research. Participants were reminded that they would not be penalised in any way if they chose not to participate in the study. With the verbal and written permission of the participants, the interviews were audio-recorded. Data was collected until data saturation was achieved after 12 interviews. During the study, the researcher made use of field notes and a reflective journal. A detailed description will follow in Chapter 3.

1.9.4 Data analysis

Data analysis is a technique that is concerned with reducing, organising and giving meaning to raw data (Burns & Grove 2011:535; Schneider et al 2013:142).

After the interviews were recorded, they were transcribed verbatim by the researcher and accuracy was confirmed by listening to the audio recordings several times until the researcher was satisfied that the transcription was accurate. Transcripts, field notes and the reflective journal were read and re-read numerous times to allow the researcher to be fully immersed in the data (Liamputtong 2013:241). Data collection and analysis occurred simultaneously during the course of the study (Creswell 2014:195). The researcher first made use of open coding in order to organise the raw data. The

researcher then moved onto thematic analysis to analyse data. Open coding involved the researcher approaching the raw data without any preconceived ideas as to how to code the data (Polit & Beck 2012:569; Tappen 2011:367). Thematic analysis is a more common type of data analysis in qualitative research. It involves identifying themes through the reading and re-reading of the raw data (Liamputtong 2013:249-250; Liamputtong & Serry 2013:375). Refer to Annexure D for coding protocol.

An independent coder was used during data analysis to ensure objectivity (Refer to Annexure J for the letter from the independent coder). A consensus discussion took place between the researcher and the independent coder to ensure themes identified correlated with the data collected. Chapter 3 describes data management and analysis in more detail.

1.10 MEASURES TO ENSURE TRUSTWORTHINESS

In qualitative research scientific rigour is ensured and determined by trustworthiness. Trustworthiness refers to the extent that the data truly represents the participants' experiences. This encompasses the concepts of credibility which is the accuracy of the presented data, transferability which is the ability of the data to be transferable and representative of other settings, confirmability which is the objectivity of the data, dependability which is concerned with whether the study could be replicated and the same conclusions drawn and authenticity which refers to providing a true report of the participants' viewpoints (Borbasi & Jackson 2016:220-221; Polit & Beck 2012:540; Schneider et al 2013:153-154). A number of measures were employed during this study to ensure trustworthiness. These included triangulation, member-checking, thick description and reflexivity. Chapter 3 describes these measures to ensure trustworthiness in greater detail.

1.11 ETHICAL CONSIDERATIONS

Before commencing with data collection the researcher received ethical clearance from the Higher Degrees Committee of the Department of Health Studies at the University of South Africa (REC-012714-039) (Refer to Annexure E). The researcher also received ethical clearance from the Hunter New England Ethics Committee in Australia

(15/02/18/4.09) (Refer to Annexure F). The researcher additionally obtained written consent from the research participants before the commencement of the study.

Due to the potential for mistreatment of research participants, the Belmont Report (1979) outlines the three ethical principles that must be adhered to when conducting research (Grove et al 2015:98; Schneider et al 2013:79). These principles are beneficence, respect for human dignity, and justice (Grove et al 2015:98; Schneider et al 2013:79). The researcher adhered to these ethical principles during the course of this study by treating the participants with respect and ensuring that no harm came to them.

Informed consent refers to a process whereby a prospective participant agrees to participate voluntarily in a study or decline participation after they have understood all the information about the study (Burns & Grove 2011:540; Hissong et al 2015:152). Since the participants were part of a vulnerable population, the researcher made sure that they were mentally stable and able to provide consent. The researcher was able to determine this during the initial telephonic conversation. The researcher did not exercise any coercion in order to make the participants take part in the study, and advised the participants that they have the right to withdraw from the study at any time. The researcher also advised that there were referrals for counselling and support if necessary, if talking about their experiences would conjure unpleasant memories. None of the participants became distressed or upset during the interviews, and no referrals for counselling were necessary.

All documents and data sources including consent forms, audio tapes, transcripts and portable disc drives will be locked in a secure filing cabinet in the researcher's home office for 15 years and will only be accessible to the researcher. Each participant selected a pseudonym that further protected their identity (anonymity). Chapter 3 describes ethical considerations in greater detail.

1.12 SIGNIFICANCE OF THE STUDY

The researcher envisions that the findings of this study will enable mental health service providers to improve service delivery by gaining a better understanding of what role social networks and social support play in the journey of mental health consumers. This, in turn, will help bridge the treatment gap and may serve to minimise the effects of the

revolving door syndrome. The study aims to provide service providers with the information they need to collaborate with the people who form part of the mental health consumer's social network and provide social support for the benefit of the mental health consumer.

1.13 LIMITATIONS OF THE STUDY

The main limitation of the study is that the nature of the qualitative approach and the small sample size (12 participants were interviewed) means that the results of the study cannot be generalised beyond the study population. However, the understanding gained may prove useful in other situations (Polit & Beck 2012:180). Chapter 5 will discuss other study limitations in greater detail.

1.14 OUTLINE OF THE STUDY

In Chapter 1 the researcher introduced the study and provided the aims and objectives of the study. The researcher also provided background information to the study along with definitions of key terms and the methodology used in the study.

Chapter 2 consists of the literature review where the researcher discusses a number of factors that impact on the mental health consumer.

In Chapter 3 the researcher provides a detailed explanation of the research methodology used during the study.

Chapter 4 is concerned with data analysis and the results.

Finally, Chapter 5 discusses conclusions, limitations and recommendations.

As stated above, this chapter has provided a general overview of the study as a whole. Chapter 2 follows with an in-depth look at the literature.

CHAPTER 2

LITERATURE REVIEW

“I’m really concerned as I’m finding very little literature on my research topic. Some literature is relevant but the sources are really dated. I need to employ the services of the subject librarian.

I’m getting really worried...”

(extract from reflective journal 25/05/2015)

2.1 INTRODUCTION

The previous chapter provided the background to the study and outlined the statement of the research problem. It also described the research objectives, research questions, definitions of key terms, and provided a general overview of what was to follow in subsequent chapters. This chapter will discuss the review of the literature in detail.

A literature review is a review of the literature related to an area of study. This review is used to clarify and evaluate the literature and relationships between the literature are identified and discussed (CQ University 2015). A literature review is necessary as it shares the results of previous studies with the reader relating to the topic being researched and also places the study in context, highlighting the gaps in knowledge (Creswell 2014:30).

There are three ways that a literature review can be used in a qualitative study. Literature can be used to contextualise the problem as part of the introduction to a study. Secondly, literature can be presented as a separate section under a ‘literature review’. Finally, the literature is presented at the end of study and is used to compare and contrast the findings of a research study (Creswell 2014:31).

For the present study, the researcher used literature as part of the introduction in Chapter 1 and will use literature in Chapter 4 to support the research findings and to conclude the study in Chapter 5. The researcher has included a separate section for the literature review in this chapter as she wanted to familiarise herself with the terminology

of the field and to explore in greater detail the information available on the research topic and also to highlight the gaps within the literature.

Throughout the review of the literature, the researcher identified that there is limited literature available on the research topic, especially with regards to recent sources that have been written within the last five years. The researcher completed searches using the following databases: Ebsco Host, Pubmed, Medline, Science Direct, Google Scholar, Sage, CINAHL and Proquest. Keywords used included: “mental illness”, “deinstitutionalisation and mental illness”, “recovery and mental illness”, “consumer participation and recovery”, “perspective of service providers in recovery”, “service providers and mental health consumers”, “non-governmental organisations and mental illness”, “community-managed organisations and mental illness”, “stigma”, “stigma and mental illness”, “social support”, “social support and mental illness”, “social networks”, “social networks and mental illness”, “access to mental health services”, “use of mental health services”, “rural mental health consumer”, “urban mental health consumer”, and “knowledge about mental illness”.

The researcher also utilised the services of the subject librarian of the College of Health Studies. The subject librarian encountered the same challenge as the researcher in terms of sourcing relevant and recent sources pertaining to the research topic.

The researcher has endeavoured to use sources within the last 5 years, but where recent sources could not be obtained, the researcher has used sources between 1993 and 2016.

In this chapter, the researcher presents literature relevant to the topic of investigation. The researcher outlines mental illness and the characteristics of severe mental illness. Other factors relating to the experience of the mental health consumer are explored. Social networks and social supports are also described in greater detail.

2.2 MENTAL ILLNESS

The Mental Health Act of New South Wales (2007:s 14) defines ‘mental illness’ as “ a condition that seriously impairs, either temporarily or permanently, the mental

functioning of a person and is characterised by the presence in the person of any one or more of the following symptoms:

- (a) delusions,
- (b) hallucinations,
- (c) serious disorder of thought form,
- (d) a severe disturbance of mood,
- (e) sustained or repeated irrational behaviour indicating the presence of any one or more of the symptoms referred to in paragraphs (a)-(d)".

Mental illness has also been described as referring to conditions that affect a person's thinking, emotions and behaviour (Australian Government 2014:2; Manderscheid, Ryff, Freeman, McKnight-Eily, Dhingra & Strine 2010:2).

The most common mental illnesses are anxiety and depressive disorders. Mental illnesses involving psychosis such as schizophrenia and bipolar affective disorder are less common but more severe (Australian Government 2014:2-3). Severe mental illness is described below in further detail.

2.2.1 Severe mental illness

When a person's mental illness affects their ability to function and leads to impairment, disability and disadvantage, this is referred to as severe mental illness (Victorian Government 2014; Herzog 2013:505). Examples of severe mental illness include schizophrenia, bipolar affective disorder, mania, and psychosis (Herzog 2013:505).

The participants in this study were all living with a severe mental illness and have diagnoses of the above, such as schizophrenia and bipolar affective disorder.

People living with a severe mental illness are likely to experience both primary and secondary symptoms. Primary symptoms are directly caused by the illness. For example hallucinations and delusions are primary symptoms of schizophrenia. Loneliness and social isolation are secondary symptoms as they are caused by a person's response to their illness (Stuart 2013:201).

2.2.2 Characteristics of severe mental illness

Herzog (2013:506) found that adults living with severe mental illness were likely to be less educated, poor, live alone and had some history of being homeless or incarcerated compared to adults without a severe mental illness. Adults living with a severe mental illness also reported more physical health problems and difficulties in participating in social activities than adults without a severe mental illness.

People living with severe mental illness often face many challenges in their recovery such as poverty, stigma and victimisation. They are also likely to be unemployed and have limited, if any, close relationships (Herzog 2013:506; Stuart 2013:201).

Those living with mental illness may experience functional difficulties in their activities of daily living and challenges in their interpersonal relationships. People living with mental illness have been described as being withdrawn and socially isolated. They may also struggle with feelings of low self-esteem, and have difficulties with motivation as a result of a fear of failure. It is, therefore, important to focus on their strengths and what they are able to achieve. Non-adherence to medication and treatment is often a characteristic of those living with severe mental illness. It is important for service providers to establish the reason for the person's non-adherence and to link the benefits of treatment and medication with a person's own goals (Herzog 2013:506-507; Stuart 2013:202-203).

The study results will be able to identify the unique challenges of living with a severe mental illness as highlighted by Stuart (2013:202-203) and Herzog (2013:506-507). These challenges include stigma and victimisation, limited interpersonal relationships, non-adherence to medication and treatment and functional difficulties.

Such individuals living with severe mental illness have historically been accommodated within institutions. However, over the process of time deinstitutionalisation has occurred (Davis, Fulginiti, Kriegel & Brekke 2012:259).

2.3 DEINSTITUTIONALISATION

Australia's structure for mental health service provision moved from institution-based care to community-based care. This deinstitutionalisation occurred in the 1960's and 1970's before adequate community supports were put in place (Krupinski 1995:577; Rosen et al 2012:389; Talbott 2004:1113).

When patients living with a severe mental illness were discharged from institutionalised care, there was a belief that their families would look after them. However, this assumption did not take into account the burden of care that would be placed on families (Krupinski 1995:577). This often led to family breakdown, which negatively impacted on the mental state of the patients. Also, a number of patients did not have families which they could return to (Krupinski 1995:577). As a result, a number of discharged patients who were living with a severe mental illness, landed up on the streets while others were transferred to nursing homes (Talbott 2004:1113).

Krupinski (1995:578) and Talbott (2004:1114) suggest that those patients living with a severe mental illness should be discharged into the community only if adequate services are available to cater for their needs. They also suggest that funds should be made available for adequate housing and financial support for patients living with a severe mental illness in the community. Patients living with a severe mental illness should have access to vocational rehabilitation and education opportunities in the community. Krupinski (1995:578) and Talbott (2004:1114) further recommend that money should follow patients living with a severe mental illness into the community, and funding needs to be flexible in order to meet the changing needs of this population continually.

In contrast, Priebe, Badesconyi, Fioritti, Hansson, Kilian, Torres-Gonzales, Turner and Wiersma (2005:123) compared the data in six European countries (England, Germany, Italy, the Netherlands, Spain and Sweden) who had all undergone deinstitutionalisation in the 1950's, 1960's and 1970's. Priebe et al (2005:124) found that all these countries had experienced reinstitutionalisation since 1990, to different degrees. Priebe et al (2005:125) describe reinstitutionalisation as a form of newly established institutionalised mental health care in the six European countries since 1990. Though the mental health systems of many nations have strived to move away from institutionalised care for those

living with mental illness, the results of this study show that some countries are returning to some form of institutionalised care.

Some of the participants in this study have experienced long-term institutionalisation while others have not. The participants in the present study were not admitted at the time of the study, or institutionalised. Deinstitutionalisation created a greater need for social support for mental health consumers. As such, deinstitutionalisation and community supports have been an important part of their recovery journey.

2.4 RECOVERY

The recovery-orientated practice was a response to deinstitutionalisation (Anthony 1993:521). Recovery has been defined as a way of living a satisfying and hopeful life where one is able to contribute to life even with the limitations caused by mental illness. Recovery is described as a deeply personal journey and involves developing a new meaning and purpose for one's life beyond the effects of mental illness (Anthony 1993:527).

Some assumptions about recovery are that: consumers hold the key to recovery; in order for recovery to be successful, consumers need a good social support network; recovery can occur even if symptoms re-occur; and recovery is not a linear process, there are often setbacks along the way (Anthony 1993:532-533).

Treatment, case management and rehabilitation are all facilitators of recovery (Anthony 1993:527). Controlled studies on Assertive Community Treatment (ACT) or Intensive Case Management (ICT) have found that this model has been associated with reduced time in the hospital and more stability in housing, thus further facilitating recovery. Other studies found that ACT or ICT had little effect on the social functioning of mental health service users particularly with regard to vocational training and time in jail (Mueser, Bond, Drake & Resnick 1998:37). The participants in the present study were case managed through their local community mental health teams. The study findings will be able to identify whether mental health professionals form part of the social networks of mental health consumers and, if so, whether they provide the social support that facilitates recovery for mental health consumers.

The internal components of recovery are also important. The individual must believe that recovery is possible and therefore have hope. They also need to focus on their strengths rather than their weakness, believe that change is possible, and be willing to move forward rather than focusing on the past. The aim of the recovery model is for consumers to resume more responsibility for themselves and their lives, and live with the consequences of those choices (Jacobsen & Greenley 2001:482-483). The external components of recovery include recovery-orientated services which focus on symptom relief, crisis intervention, rehabilitation, case management, and advocacy (Jacobsen & Greenley 2001:484).

Recovery from a severe mental illness is seen as the improvement of symptoms whereby a person is able to return to baseline or near baseline functioning, following the onset of their mental illness (Davidson & Roe 2007:463). Other people are unable to recover as per this definition. The term 'recovery' in mental illness refers to a person who is pursuing their life's aspirations though the symptoms of illness persist. This means that a person may live a dignified and meaningful life in the face of ongoing symptoms (Davidson & Roe 2007:464).

Recovery-orientated practice has become a critical philosophy within the mental health field (Jacobson & Greenley 2001:482). Recovery is an essential part of mental health consumers' journey of living with mental illness. As part of the recovery philosophy, mental health consumers are encouraged to participate in their own treatment and journey towards recovery (Jacobson & Greenley 2001:482).

2.4.1 Consumer participation

Lammers and Happell (2003:390) conducted a qualitative study in the experience of consumers with regards to participation in mental health services. The findings of their study indicated that mental health consumers need to be provided with the opportunity to participate in the planning, implementation and evaluation of the mental health services they receive. The participation of mental health consumers is dependent on each mental health consumer's level of functioning and how much they wish to contribute. Lammers and Happell (2003:390) highlighted that each mental health consumer should be considered as an individual, and mental health consumers should not be treated as a homogenous population.

Lammers and Happell (2003:390) found that consumer participation was strengthened when there were processes in place that allowed for consumer involvement within their care.

Mental health consumers also expressed that the attitudes of mental health service providers were a barrier when it came to consumer involvement as some providers appeared to be of the opinion that mental health consumers had nothing valuable to contribute pertaining to service delivery (Lammers & Happell 2003:391).

There has been an evolution in the way mental health services have been delivered. The continuing challenge is in redefining the relationship between the mental health consumer and the service provider. The traditional role of service providers is to assume responsibility for the care of consumers without the opportunity for consumers themselves to influence the process (Lammers & Happell 2003:386). Within the recovery-orientated framework, it is important for consumers to take the leading role in their recovery with service providers as partners. The study findings will identify the role that mental health consumers feel that service providers play in their recovery journey while living with a severe mental illness.

2.4.2 Perspective of service providers

Health care providers identify that some of the barriers affecting individuals living with mental illness include: limited finances, fear, stigma, and lack of social support. Health care providers recognise that stigma significantly affects an individual's help-seeking behaviour.

Health care providers also expressed that individuals living with mental illness often display a sense of disempowerment and lack of control over their lives. Health care providers report that the physical health concerns of individuals with mental illness were often treated as secondary to their mental health concerns (McCabe & Leas 2008:309).

The perspective of health professionals or service providers is critical as they provide many of the mental health services utilised by mental health consumers. The study aims to identify the role that social networks and social supports play in mental health service utilisation so that their role can be enhanced. Service providers can also form part of the

social networks of mental health consumers. Apart from traditional mental health services, Non-governmental Organisations/Community-managed Organisations are a growing sector within mental health services in Australia, and they provide informal care and support to mental health consumers (Pols & Oak 2011:5).

2.4.3 Non-governmental organisations/ community-managed organisations

Non-governmental or community-managed organisations are not for profit organisations that aim to provide comprehensive care to individuals living with mental illness. Thus, community-managed organisations form an important part of mental health consumers' social networks and support. The care provided by community-managed organisations includes supported employment, education, family and carer support, rehabilitation, social inclusion, recovery and relapse prevention. This is the fastest growing sector within mental health services in Australia (Pols & Oak 2011:5). The Mental Health Carer Respite Program and the Community-Based Program are specific programmes targeting carers and families as a way to support them and decrease their burden of care (Bateman & Smith 2011:51).

When people diagnosed with a mental illness engage with community-managed organisations, they seem to have improved health outcomes (Bateman & Smith 2011:65). By participating in rehabilitation and support services, people diagnosed with a mental illness stay out of hospital and remain well for longer periods of time (Bateman & Smith 2011:65; Bateman, Rosen, Smith & Hughes 2010:19). Community-managed organisations play a supportive role in reducing the frequency, duration and intensity of mental illness episodes. As a result, it frees up specialist treatment services for those who are acutely unwell, thus decreasing the demand for overburdened medical services (Bateman & Smith 2011:65; Bateman et al 2010:19). The role of community-managed organisations is becoming increasingly important due to their outcomes of helping individuals living with a mental illness and their carers participate in community life. As mentioned before, community-managed organisations provide a variety of support services that are recovery-orientated. They also assist individuals living with mental illness access more mainstream mental health services (Bateman & Smith 2011:57).

Although community-managed organisations support mental health consumers in their recovery journey, stigma is one of the barriers that mental health consumers face when seeking help for their mental illness (Fuller, Edwards, Procter & Moss 2000:150).

2.5 STIGMA

Mental health problems are associated with a high degree of stigma. Consequently, people may avoid seeking help within formal mental health services even though they may recognise their own distress (Fuller et al 2000:150-151; Venkatesh, Andrews, Mayya, Singh & Parsekar 2015:449).

Stigma is described as having four components: labelling, stereotyping, separation, status loss and discrimination (Barczyk 2015:40; Link & Phelan 2001:363). Labelling is concerned with something that is affixed and maintains the focus on a particular difference. The next component of stigma occurs when the labelled differences are linked to stereotypes when a label links the person to a set of undesirable characteristics that form the stereotype. When a labelled person is believed to be different, stereotyping can be easily accomplished. In extreme cases, the stigmatised person is thought to be different from “us” and therefore not really human. The fourth component is concerned with status loss. When labelled people are linked to undesirable characteristics, a rationale is constructed devaluing and excluding them. This causes them to experience status loss and discrimination. Discrimination occurs as a result of a loss of status on the human or social hierarchy. A person who develops a severe mental illness may form expectations that others will reject them or discriminate against them based on their mental illness as a result of their worldview or belief that people living with mental illness are rejected or stigmatised. Depending on the extent that this forms part of the person’s worldview, this perception can have negative consequences, such as a person avoiding contacts they perceive as threatening (Link & Phelan 2001:368-374; Link, Wells, Phelan & Yang 2015:118-119).

Thornicroft, Rose, Kassam and Sartorius (2007:191) describe stigma as a combination of a lack of knowledge (ignorance), attitudes that people hold (prejudice), and their behaviour (discrimination).

Thornicroft et al (2007:192) and Ungar, Knaak and Szeto (2016:262) propose that research and action should move from focusing on stigma to focusing on discrimination. For example, instead of asking an employer whether they would hire a person with a mental illness, it should be assessed in practice whether or not the employer does.

Stigma has many consequences for those who are stigmatised. They may experience decreased life opportunities such as reduced social contacts, limited employment opportunities, limited housing options, and underutilisation of health services in order to avoid being stigmatised (Sickel, Seacat & Nabors 2014:204; Yang, Cho & Kleinman 2008:219). For those living with a mental illness, further adverse effects of stigma include low self-esteem, depression, limited social networks and non-compliance with treatment programmes (Cruwys & Gunaseelan 2016:36; Link, Struening, Neese-Todd, Asmussen & Phelan 2001:1621; Yang et al 2008:227). Link et al (2001:1621) and Sickel et al (2014:204) therefore saw that one way of reducing the impact of stigma on those living with a severe mental illness was to improve their self-esteem.

Other ways that stigma can be combated is through protest, education and contact. Protest involves the active participation to reduce stigmatising images in the media in an effort to reduce stigmatisation. With education, inaccurate information regarding stigmatised groups can be challenged, and the media can be used as a tool to provide accurate information. Contact involves having personal contact with a person from the stigmatised group. For example, meeting a person living with a mental illness in order to decrease stigma and stereotyping (Sickel et al 2014:206; Ungar et al 2016:267; Yang et al 2008:228-229).

On the other hand, Whitley and Campbell (2014:3-4) found that their participants (who were all living with a severe mental illness) did not experience stigma as a common problem, as very few stigmatising encounters were reported. The participants had a diagnosis of schizophrenia, bipolar affective disorder, major depression and schizoaffective disorder and were community residents. This is very similar to the participants in the present study. The participants also did not describe stigma as a barrier to their recovery. They rather viewed stigma as a potential problem and were keenly aware of it. The participants were also fearful of being stigmatised by others. As such, they developed various behavioural and psychological strategies in order to prevent an experience of stigma. These strategies are mostly concerned with blending

in and fitting in and to “look normal” through what they wore, their personal appearance, behaviour and demeanour.

The researcher is interested to discover whether the participants from the present study experience stigma from their social networks.

Social support is correlated with perceived stigma (Mueller, Nordt, Laubner, Rueesch, Meyer & Roessler 2006:46). Kido, Kawakami, Miyamoto, Chiba and Tsuchiya (2013:243) found that living in a community with high social capital (this includes social networks and community engagement) led to lower stigma towards those living with mental illness. Social support is further discussed below.

2.6 SOCIAL SUPPORT

Puyat (2013:598) defined ‘social support’ as “the subjective perception that help is available when needed and that one is valued by other people”. Maulik, Eaton and Bradshaw (2011:30) agree with this definition and further state that social support is related to one’s social network, and as such, social support acts as a coping mechanism for those living with mental illness.

According to Chinman, George, Dougherty, Daniels, Ghose, Swift and Delphin-Rittmon (2014:429) and Davidson, Chinman, Kloos, Weingarten, Stayner and Tebes (1999:165), individuals living with severe mental illness have been found to benefit from peer support. These authors describe that peer support may take on three forms. Firstly, there are the naturally occurring mutual support groups, secondly are consumer-run services where those living with a mental illness volunteer to run groups to support other mental health consumers. Finally, consumers can be employed as paid providers in clinical and rehabilitative settings. Studies on mutual support groups found that they promoted larger social networks and recovery among those living with severe mental illness (Chinman et al 2014:429; Davidson et al 1999:165). Consumer-run services and employment of consumers suggest that they may be able to broaden access to peer support for those living with severe mental illness (Chinman et al 2014:429; Davidson et al 1999:165). Austin, Ramakrishnan and Hopper (2014:881) completed a mixed methods study on those formally employed as peer supporters in New York community mental health settings. Austin et al (2014:881) found that these peer supporters viewed

their role as transforming their lived experience as mental health consumers to help other mental health consumers navigate the mental health system. Secondly, the peer supporters saw their role as providing tangible evidence to others (especially mental health consumers) that recovery was possible. Finally, the peer supporters saw their role as launching mental health consumers towards their own recovery.

Davidson, Chinman, Sells and Rowe (2006:443) reviewed the data from four randomised controlled trials on the role of peer support (those who run consumer services or employed in clinical settings) as mental health treatment. The results from the randomised controlled trials highlighted that there was very little difference in terms of outcomes between conventional care and care provided by peers (peer support). Davidson et al (2006:443) concluded that peer support is still in its early development as a form of mental health treatment or service, but encourages further exploration. These findings were further supported by Llyod-Evans, Mayo-Wilson, Harrison, Istead, Brown, Pilling, Johnson and Kendall (2014:14), who conducted a systematic and meta-analysis of randomised controlled trials. Llyod-Evans et al (2014:14) found that despite the popularity of peer support programmes internationally, the randomised controlled trials concluded that there was very little difference in terms of outcomes for people living with severe mental illness. Llyod-Evans et al (2014:14) also encourage further exploration.

The quality of social support that people with mental illness have is positively associated with the development of a sense of coherence where one has confidence in their own ability to cope (Langeland & Wahl 2009:834).

Both social network size and social support are correlated with better recovery in individuals living with severe mental illness (Hendryx, Green & Perrin 2009:325; Rogers, Anthony & Lyass 2004:437). Low levels of social support have been associated with low self-perceived mental health. Increased social support has also been associated with smaller urban centres (Chadwick & Collins 2015:228).

Social support is correlated with perceived stigma. The more social support people perceive at the time of hospitalisation, the less they think that people will reject them because they have a mental illness. However, if people perceive less social support, they tend to feel more stigmatised (Mueller et al 2006:46).

Higher levels of social support have also been associated with greater use of general medical services but lesser use of specialised mental health services (Maulik, Eaton & Bradshaw 2009:1222). Maulik et al (2011:29) found that social support, rather than social networks, increased mental health service use after a person had experienced a life event such as bereavement, divorce, having a child, losing a job, moving house or battling a life threatening illness.

Social support has conversely been found to prevent a person's entry to mental health services until a person's condition is such that they require treatment. In the case that a person requires mental health treatment, having social support increased the probability of mental health service utilisation (Thoits 2011a:4).

Social supports complement social networks which are discussed further below.

2.7 SOCIAL NETWORKS

Social networks have been described as the number of social contacts one has and the frequency with which they interact with them (Maulik et al 2011:30).

Individuals living with a severe mental illness have been found to have smaller social networks than the general population. A person's social network may influence their use of mental health services. Smaller social networks and less social support are associated with more frequent hospitalisation (Albert, Becker, McCrone & Thornicroft 1998:248). High density and low density social networks are associated with more time spent in hospital for those living with a severe mental illness. Medium density social networks are optimal as these can be maintained under stress. Lower levels of social support are also associated with poorer outcomes (Albert et al 1998:250).

Social networks matter for health outcomes (Perry & Pescosolido 2015:116). When individuals who are living with a mental illness are in an acute episode of illness, they activate their network ties, who are the individual people in their social networks. Individuals living with a mental illness will typically choose someone with experience of mental illness. Those who activate adequate support networks report better outcomes than those who activate weaker network ties by not being selective in their approach (Perry & Pescosolido 2015:116).

A person's social network plays an important role in their help-seeking attitudes and behaviour for psychological services that address mental health issues. Those who seek help from mental health services are prompted to do so 74% to 78% of the time. Those who had sought help do so because they know someone who had sought help 92% to 95% of the time and because of this, the person seeking help has a more positive expectation about treatment and what friends and family would think of them if they seek help (Vogel, Wade, Webster, Larson & Hackler 2007:241).

Müller, Nordt, Lauber and Rössler (2007:571) in their longitudinal study of people living with a severe mental illness, found that the participants' social network diversity increased over the period of the study (approximately 5 years). However, the participants' perception of social support did not change. Most of the participants had relatives, friends and co-workers, while only a small number reported having partners and or children. Women were found to have more diverse social networks while men, without a job or having a low income, were associated with less diverse networks. Participants without close friends perceived less support while those with partners and friends found them very supportive.

Müller et al (2007:571) concluded that people living with severe mental illness may not necessarily be isolated in terms of their social network diversity as they do have people to turn to. However, access to fulfilling certain social roles, such as being a partner or parent, is limited.

There are different types of social networks: the socially excluded or truncated network, the homogeneous network, the traditional network, the heterogeneous network, and the network of solidarity. The socially excluded or truncated network consists of a small number of people in a small number of groups. Examples include the unemployed and newcomers. The homogeneous network has a limited number of groups but extensive contacts within these groups. These contacts are made up of extended family, local friends and neighbours. An example of this is single mothers. The structure of a traditional network is tight knit and consists of family, neighbours, friends from social clubs, sports or school, and ex-colleagues. Examples of this are the elderly who tend to have spent most of their lives in a certain area. The members of a heterogeneous network are different in terms of age, employment, culture and interests. Heterogeneous networks are open and loose knit. Examples are people involved in volunteer

organisations. The network of solidarity consists of members who are both similar and dissimilar and so the network structure is both tight and loose. This is a blend between the traditional and heterogeneous networks (Cattell 2001:1507).

In general, social networks have been linked to positive or negative attributes depending on the types of social networks you are a part of. Those with more restricted social networks are more likely to express feeling anxious, depressed and socially isolated. Those with more extensive networks, in turn, express hope for the future and feel more in control of their lives (Cattell 2001:1508-1509).

In this study, the researcher seeks to discover what social networks mental health consumers have and how these influence their use of mental health services.

2.8 ACCESS TO MENTAL HEALTH SERVICES

As a result of either the side effects of medication or the actual illness itself, individuals living with mental illness find it difficult to access mental health services (Bambling, Kavanagh, Lewis, King, King, Sturk, Turpin, Gallois & Bartlett 2007:127; Mental Health Council of Australia [s.a.]:2). If they reside in rural or remote areas, access is more difficult due to limited or no public transport options. Persons living with mental illness may also face difficulty in understanding the information communicated to them due to their illness and the side effects they may be experiencing (Bambling et al 2007:127; Mental Health Council of Australia [s.a.]:2).

Mental health consumers are often unaware of what options are available and how to access mental health services. Health professionals may also be unaware of what services exist and how to navigate the health system, which at times appears fragmented (Mental Health Council of Australia [s.a.]:2).

In Australia, the first point of contact for mental health concerns is the General Practitioner (GP) (Bambling et al 2007:127; Mental Health Council of Australia [s.a.]:3; Parslow & Jorm 2000:997). Persons living with mental illness are finding it increasingly difficult to access care through GP's. Firstly, there is a decrease in the number of bulk-billing GP practices which means that a number of mental health consumers need to pay upfront for all their appointments. Mental health consumers also face great difficulty

in identifying or accessing GP's with a special interest in or knowledge of mental health. There are additional challenges in obtaining short notice appointments with GP's during a mental health crisis (Bambling et al 2007:127; Mental Health Council of Australia [s.a.]:3).

Bambling et al (2007:128) conducted a study on mental health services among GP's, allied health professionals, and non-profit organisations. The findings revealed that all services identified that there was inadequate care for people with mental health problems with a tendency to respond to crisis rather than to offer services that focus on early intervention or relapse prevention. GP's emphasised that they were unable to obtain outpatient mental health services for their patients. They cited shortage of mental health providers and inadequate coverage as the main barriers to mental health service access (Cunningham 2009:490).

There is reduced accessibility of mental health services in rural areas, and rural staff often take on diverse roles in order to fill service gaps (Rajkumar & Hoolahan 2004:78; Turpin, Bartlett, Kavanagh & Gallois 2007:132).

In rural and remote communities there are frequently problems with the recruitment and retention of staff (Rajkumar & Hoolahan 2004:78; Turpin et al 2007:132). Other barriers include inadequate services for those in crisis, concerns about treatment quality, over-extended human resources, and poor communication between services. People diagnosed with a mental illness living in rural or remote areas were identified as having inadequate access to housing and transport (Turpin et al 2007:132).

Treatment coverage for mental disorders is poor in many developed countries (Andrews, Issakidis & Carter 2001:417). Approximately one-third of people living with mental health disorders in developed countries use mental health services (Andrews et al 2001:417; Ngui & Vanasse 2012:195). Weinhold and Gurtner (2014:201) found that many developed nations struggled to ensure that services in rural areas were equitable. Rural areas were characterised by shortages of service providers, decreased quality of care, barriers to access, and the inefficient utilisation of available services. These problems are related to physical infrastructure, educational, economic and political issues.

Padgett, Patrick, Burns and Schlesinger (1994:222) conducted a study in an insured “non-poor” population in America. The results of their study highlighted that Blacks and Hispanics’ use of out-patient mental health services was lower than that of Whites. The Blacks and Hispanics made use of informal supports such as community members or religious institutions such as churches. Padgett et al (1994:222) concluded that ethnic differences exist in the use of mental health services even when factors such as socioeconomic and insurance factors are accounted for. These authors (1994:222) proposed that other factors, such as cultural or attitudinal factors and barriers to accessing mental services, may be responsible.

2.8.1 Use of services

People from all categories of mental health disorders (mild, moderate and severe) who utilise mental health services have been found to visit GP's more often than those living with mental health disorders who did not utilise mental health services. Those with severe mental illness visited GP's more often than those living with less severe mental illness. There is no difference in service use whether the person lives in a rural, remote or metropolitan area (Mai, Holman, Sanfilippo, Emery & Stewart 2010:505). Women, and those with a diagnosed affective, anxiety or substance use disorder are also more likely to use mental health services (Parslow & Jorm 2000:997).

In Australia, it is common for rural and remote mental health consumers to be transferred over long distances in order to access tertiary mental health services which are located in larger regional or metropolitan areas. As such, there are often difficulties with integrating their care between primary and tertiary services (Taylor, Edwards, Kelly & Fielke 2009:216). Whiteford and Buckingham (2005:396) found that by 2002 there were disparities between states and territories in terms of per capita spending on mental health services. This, in turn, has resulted in a wide variation of mental health services available across Australia.

Mental health consumers who are transferred to the city for mental health treatment see this as beneficial despite being transferred over long distances and being separated from friends and family as they have access to specialised mental health care. Service providers in rural and remote areas, however, report that they found the transfer of care

difficult due to information flow and integrating primary and tertiary services (Taylor et al 2009:216).

McCabe and Leas (2008:307) discovered that participants who were living with a mental illness had a high level of awareness of the range of health services available to them and regularly accessed these. These included mental health and general medical services. The authors (McCabe & Leas 2008:308) further found that participants living with a mental illness also disclosed that they were afraid of attending medical appointments by themselves and the difficulties they have in articulating their health concerns.

Participants from McCabe and Leas' (2008:308) study who were diagnosed with mental illness identified barriers to health care services such as finding that doctors did not take their physical concerns seriously. They also found their treating doctors impersonal towards them. The participants highlighted that limited transport impacted on their ability to access medical care. These participants were dissatisfied with the health care services they received as they felt health care providers did not provide holistic care.

Continuity of care has been deemed an important part of quality care in mental health services by both mental health consumers and service providers alike (Jones, Ahmed, Catty, McLaren, Rose, Wykes & Burns 2009:632). Both mental health consumers and carers highlight that they experience the repeated changes in staff very frustrating during the course of their care. The mental health consumers find it frustrating having to re-tell their story, and the carers find this frustrating in terms of the emotional demands placed on the mental health consumers. This aspect interrupts their therapeutic relationships with staff (Jones et al 2009:634).

Carers and mental health consumers further highlight the tendency of services to respond only to crisis rather than acting in a preventative manner. Mental health consumers and carers also disclosed that there were many communication gaps between different service providers and agencies involved in their care and this further contributed to discontinuity of care (Jones et al 2009:636).

2.8.2 Rural mental health consumer versus urban mental health consumer

Rural communities experience economic difficulties as a result of loss of industry and population, high levels of unemployment, and disadvantage. This has an impact on the mental health of rural communities (Fuller et al 2000:151).

The isolation of rural and remote communities has produced a culture of self-reliance. This culture of self-reliance means that rural and remote communities are used to meeting their own needs without outside help. This influences the help-seeking behaviour of rural and remote communities with regards to mental health problems (Fuller et al 2000:151).

Riva, Curtis, Gauvin and Fagg (2009:657-658) claim that people living in rural areas were less likely than urban dwellers to report their health as being fair or poor, or report common mental disorders. There were significant variations in health across semi-rural areas and urban areas.

It has been previously noted that rural and remote residents have difficulty accessing high quality mental health services. Some of the challenges that face rural and remote mental health consumers include travelling long distances in order to reach services, difficulty accessing transportation, and increased time out of work or school. Telemedicine or video-conferencing has been one of the ways that health services have developed in order to provide psychiatric services to these rural communities to improve service delivery (Shealy, Davidson, Jones, Lopez & deArellano 2014:1).

Telemedicine or video-conferencing has been increasingly employed in rural and remote areas to respond more timely to mental health emergencies or crises. This has meant that regardless of the distance, rural and remote residents can have immediate access to a mental health assessment by a psychiatrist. This, in turn, has resulted in a decreased need for hospitalisation in some cases (Saurman, Perkins, Roberts, Roberts, Patfield & Lyle 2011:453).

High suicide rates have been reported in men (in particular young men) in rural areas (40.4 per 100000) and remote areas (51.7 per 100000), compared to metropolitan populations (31.8 per 100000). There is no significant difference between young men in

rural and remote areas who reported a mental health disorder when compared to their metropolitan counterparts. However, young men from rural and remote areas are less likely than young men from metropolitan areas to seek professional help for a mental disorder (Caldwell, Jorm, & Dear 2004:10).

Smith, Humphreys and Wilson (2008:56) found that rurality (living in a rural area) does not necessarily lead to rural-urban disparities but that rurality may intensify or exaggerate the effects of decreased availability of services, more hazardous occupations and higher personal risk, decreased access to transport and social-economic disadvantage.

Those living in rural areas have been found to have poor knowledge of mental illness when compared to those living in urban areas (Wrigley, Jackson, Judd & Komiti 2005:516). Knowledge about mental illness is discussed in more detail below.

2.8.3 Knowledge about mental illness

Rüsch, Evans-Lacko, Henderson, Flach and Thornicroft (2011:675) found that individuals who had greater knowledge about mental illness and a positive attitude were more likely to seek help for mental health problems than those who had limited knowledge and a more negative attitude towards mental illness. Individuals with a greater knowledge of mental illness were also more likely to disclose their own diagnosis of a mental illness. Rüsch et al (2011:675) concluded that help-seeking and disclosure in the general population about mental illness may be increased by initiatives that provide greater knowledge about mental illness and also promote positive attitudes towards mental illness.

Knowledge about physical health matters in the general population has been widely accepted however, knowledge about mental issues or concerns (mental health literacy has lagged behind (Jorm 2000:396). Jorm (2000:396) found that many members of the general public fail to recognise common mental disorders and psychological distress in others. Jorm (2000:396) concluded that if mental health literacy in the general population is not improved, this may impact on members of the general population from accepting evidenced-based mental health care and those experiencing mental health

disorders from accessing the appropriate care and gaining support from their community.

Hugo, Boshoff, Traut, Zungu-Dirwayi and Stein (2003:715) also found considerable misunderstanding with regards to mental illness related to stigma. Mental illness was not seen as a medical disorder but rather as stress-related or a lack of willpower. This, in turn, influenced preferred treatment and help-seeking behaviour.

2.9 CHAPTER SUMMARY

This chapter focused on presenting relevant literature to the study. Definitions of mental illness and severe mental illness were discussed. The impact of deinstitutionalisation on mental health services and recovery was debated. Finally, social networks and social support were explored in depth along with the knowledge about mental illness. The literature highlighted that there were limited studies pertaining to the research topic.

The main gap identified is that there are limited sources relating to the research topic with the majority of studies being completed in the 1990's and early 2000's. The present study seeks to add updated knowledge to the area of social networks and social support. The researcher identified no previous studies had been conducted that investigate the role of social networks and social support on mental health service utilisation by mental health consumers in rural New South Wales. The present study aims to address this research gap.

Chapter 3 outlines the research methodology used in this study that demonstrates how these research gaps were addressed.

CHAPTER 3

RESEARCH METHODOLOGY

“I am worried that my previous experience as a clinician working within mental health may cause me to overlook some areas I should uncover. I need to account for this in my methodology...”

(extract from reflective journal: 10/06/2015)

3.1 INTRODUCTION

Chapter 2 provided the review of the literature while this chapter describes the research design and methodology employed in this study. This includes the setting, population, sample, data collection, data analysis, methods to ensure trustworthiness and ethical considerations.

3.2 RESEARCH DESIGN

Quantitative research collects and analyses numerical data which inform when, how often, or how effective particular interventions or treatments are. Quantitative research does not aim to understand the personal experiences of research participants (Richardson-Tench, Taylor, Kermode & Roberts 2011:7; Schneider et al 2013:104). Qualitative research intends to understand naturally occurring social events through exploring the attitudes, beliefs, values, experiences and meanings of research participants (Richardson-Tench et al 2011:9; Schneider et al 2013:105). Therefore, in order to fully appreciate the experience of mental health consumers and the influence that their social networks and social support have on their mental health service utilisation, a qualitative approach was chosen for this study.

3.2.1 Qualitative research approach

Qualitative research is closely aligned with the constructivist tradition, which believes that human beings are inherently complex, and have the ability to create their own experiences (Hissong et al 2015:95; Polit & Beck 2012:14). Qualitative research is

subjective and is based on narrative material. Such methods aim to get a deeper understanding of the factors that contribute to human behaviour. Qualitative studies use smaller samples in order to limit the focus of the study and gain a deeper understanding of the phenomena being studied (Hissong et al 2015:95; Polit & Beck 2012:14).

Yin (2011:7-8) states that qualitative research has the following five features or characteristics:

Qualitative research studies the meaning that people ascribe to their lives in their natural surroundings and seeks to represent the views of the participants in a study. Qualitative research aims to understand the context in which people live and to contribute to the emerging knowledge that will help explain human behaviour. Finally, qualitative research aims to use multiple sources of evidence rather than a single source. During the study, the researcher sought to be true to these five features of qualitative research by gathering data in the participants' natural surroundings (for example in their homes if they felt comfortable) and attempting to understand the meaning they gave to their experiences of social networks and social support. The researcher aimed to represent the views of the participants in the study and immersed herself in participants' contexts through observation. The researcher used both observation of the participants and their environment, along with field notes with individual interviews as sources to gather evidence or data. She anticipated that the knowledge gained from the study could help explain human behaviour, in particular, the factors that influenced mental health service utilisation by the participants.

A generic qualitative, explorative, descriptive and contextual design was applied to the study.

3.2.2 Generic qualitative design

Generic qualitative designs claim no particular methodological roots but may exhibit some characteristics of other methodologies or approaches. For example, the generic qualitative design may use techniques of ethnography, grounded theory and phenomenology but not claim it as such (Polit & Beck 2012:505).

- **Exploratory design**

An exploratory research design aims to explore the phenomena under study. Exploratory research also intends to develop or refine hypotheses between the phenomena (Polit & Beck 2012:727). In the present study, this design was used to explore information about the experiences of mental health consumers and the social support and social networks they have in their lives. Exploratory designs are often used when very little is known about the phenomena under study (Polit & Beck 2012:727). This was important in this study since little information is available about the social support and social networks of rural mental health consumers.

- **Descriptive design**

Descriptive research describes concepts and relationships (phenomena) in real life settings. Descriptive research is also concerned with the accurate description of the characteristics of the phenomena under study (Burns & Grove 2011:536; Polit & Beck 2012:725). The researcher aimed to describe how the mental health consumers' experiences of their social support and social networks, impact on their use of mental health services.

- **Contextual design**

In a contextual research design, the phenomena are studied in naturalistic settings. These naturalistic settings are uncontrolled real-life situations (Burns & Grove 2011:35). The researcher collected data in the communities where mental consumers lived. The interviews were conducted in a naturalistic setting, mostly in the participants' homes where they felt most comfortable. The researcher also collected data through observation, the use of field notes and a reflective journal.

Since the generic qualitative design does not have a guiding set of philosophical assumptions, it focuses on the general characteristics of qualitative research:

- **Natural setting**

Qualitative researchers tend to collect data where participants experience the issue or problem. Research participants are not brought to a contrived environment such as a lab, nor are data collection instruments sent out to the participants to complete (Creswell 2014:185). During this study, data was collected through face-to-face semi-structured interviews in an environment where the participants felt most comfortable.

- **Multiple sources of data**

Qualitative researchers make use of various forms of data collection strategies such as interviews, observations, documents and audio-visual information, rather than relying on a single data source (Creswell 2014:185; Hissong et al 2015:105; Polit & Beck 2012:487). In this study, the researcher made use of semi-structured interviews, field notes and a reflective journal as means of data collection. The data sources were used to reflect participants' meanings.

- **Participants' meanings**

During the qualitative research process, the researcher strives to learn the meaning that the participants hold about the issue or problem under study, not the researcher's own meaning (Creswell 2014:186). The researcher strived to learn the meanings that the participants held regarding social support, social networks and their utilisation of mental health services. The researcher was also able to ensure that participants' meanings were captured by quoting the participants directly and by using probing to clarify during individual interviews. Qualitative research is an emergent design that changes to ensure a true reflection of participants' meanings.

- **Emergent design**

Qualitative research is emergent since, during the process of research, the plan may change as new information comes to light during data collection. As a result of this, the questions may change, or data collection may need to be modified (Creswell 2014:186; Polit & Beck 2012:487). During the present study, the researcher sought to be flexible and adapt the research accordingly, in line with the new information that came to light

once data collection had commenced. For example, when conducting the pilot interviews the researcher was able to identify questions that were unclear and modify these appropriately. The researcher used reflection to ensure she stayed true to the design and objectives of the study.

- **Reflexivity**

During qualitative research researchers reflect on their own personal background and experiences and how these may influence their interpretation of the research findings and shape the direction of the study (Creswell 2014:186; Liamputtong 2013:29-30; Polit & Beck 2012:487). The researcher reflected on her own personal background, beliefs, values and assumptions and how these may have influenced her interpretation of the research findings and recorded these in a fieldwork journal prior to the commencement of the study, as well as during the course of the study.

The researcher chose the generic qualitative design as it was the most suitable design to answer the research question and objectives, while taking into account the resources available to the researcher. By using a generic qualitative design that is descriptive and explorative in nature, the researcher sought to explore and describe the experience of mental health consumers and what their perceptions were when it came to social support and social networks. The researcher also attempted to gain a deeper understanding of the influence of these social networks and social support on mental health consumers' utilisation of mental health services.

3.4 RESEARCH METHODOLOGY

The research methodology will be discussed in terms of the research setting, population, sampling and sample, data collection, and data analysis.

3.4.1 Research setting

The study was completed in the northern region of New South Wales which is also known as the New England North West Regions of New South Wales. The region consists of rural and remote towns. The main population areas of the region are Armidale, Barraba, Bingara, Glen Innes, Gunnedah, Guyra, Inverell, Manilla, Moree,

Moree, Narrabri, Quirindi, Tamworth, Tenterfield, Uralla, Walcha and Wyallda. The region covers a land area of 98,606 square kilometres with a population of 183 000 (Regional Development Australia 2016). According to the 2011 census, of the main population centres, Barraba has the smallest population of 1 700 people, and Tamworth has the largest population of 56 000 people (Tamworth Regional Council 2016). There are other smaller towns interspersed among the main population centres. The northern region has one acute mental health unit, which has a capacity of 25 beds. There is also one voluntary mental health unit with a capacity of eight beds. There are three community mental health teams that service the three districts. The Peel community mental health team services Tamworth Regional, Walcha, Liverpool Plains and Gunnedah. The Tablelands community mental health team looks after Uralla, Armidale Dumaresq, Guyra, Glenn Innes and Tenterfield. The Mehi community mental health team takes care of Narrabri, Moree Plains, Gwydir and Inverell. The residents of the northern region need to travel long distances in order to reach metropolitan centres for more specialised care. This is the region from where study participants were recruited. **Figure 3.1** shows the map of the northern region. Study participants were recruited from Tamworth Regional, Armidale Dumaresq, Gunnedah, Narrabri and Moree.



Figure 3.1: Map showing the northern region of New South Wales where the study was conducted (study setting) Source: Regional Development Australia 2016

3.4.2 Population

The target population is the total population that forms the focus of the study (Imms & Greaves 2013:171). The target population from which the research participants were recruited were adults living in a rural area of the northern region of New South Wales, who had a diagnosis of a severe mental illness that was chronic and enduring in nature, and who have accessed mental health services. The accessible population is the number of cases that meet the selection criteria and are accessible for the purposes of the study (Polit & Beck 2012:274). The accessible population included the participants who were available and willing to participate after being informed about the study.

The researcher placed flyers at local mental health services and clubhouses in surrounding rural towns in order to locate potential participants for the study (Refer to Annexure A).

The researcher considered the guidelines of Creswell (2013:76), as well as Polit and Beck (2012:495), when developing the selection criteria for the proposed participants. Both authors highlight that participants should be selected from individuals who have experienced the phenomenon under study.

3.4.3 Sampling and sampling technique

Qualitative researchers make use of non-probability sampling when selecting research participants (Wood & Ross-Kerr 2011:155). In non-probability sampling, research participants are not selected randomly such as in probability sampling, but rather based on some characteristic that is of interest to the researcher (Hissong et al 2015:70; Richardson-Tench et al 2011:103).

The researcher made use of purposive sampling and convenience sampling in order to select research participants. Convenience sampling is sometimes referred to as volunteer sampling (Liamputtong 2013:15; Polit & Beck 2012:517). Purposive sampling involves the deliberate selection of participants who are information rich and thus yield data that is rich and plentiful and relevant to the study (Creswell 2013:156; Liamputtong 2013:14; Polit & Beck 2012:517; Yin 2011:88). In other words, purposive samples have an over-representation of people or events that are of particular interest to the

researcher. As a result of this, they are not a representative sample of the population being studied. When deciding to use purposive sampling, the researcher needs to map out potential respondents before deciding whom to sample. This is what distinguishes purposive sampling from convenience sampling. Purposive sampling is more rigorous and systematic (Polit & Beck 2012:518).

The most widely used method of purposive sampling is maximum variation sampling. In maximum variation sampling participants are purposely selected from various dimensions of interest. This is done by selecting participants from a wide variety of perspectives and backgrounds (Creswell 2013:156-157; Polit & Beck 2012:517). During the present study, the researcher made use of maximum variation sampling by making sure both males and females were represented, along with participants with different severe mental illness diagnoses and cultural backgrounds. By making use of participants from a variety of perspectives, this decreased bias in the study and provided the present study with more depth and understanding.

Lund Research Ltd (2012) identified the followings strengths and limitations of purposive sampling:

3.4.3.1 Strengths of purposive sampling

1. Purposive sampling has a wide range of sampling techniques that can be used across different qualitative research designs.
2. The various purposive sampling techniques can provide researchers with justifications to make generalisations from the sample that is being studied.

3.4.3.2 Limitations of purposive sampling

1. Purposive sampling is prone to researcher bias as the purposive sample is based on the judgement of the researcher.
2. Since purposive sampling is a type of non-probability sampling and is subjective in the selection of research participants, it is often difficult to defend the representativeness of the sample.

As stated before, the researcher made use of maximum variation sampling and ensured that participants from a variety of perspectives were included in the sample in order to reduce bias. Research participants were both men and women, were different ages, and were from diverse backgrounds.

A convenience sample is used when potential participants need to come forward and identify themselves (Liamputtong 2013:15; Polit & Beck 2012:517). During this study, participants who were conveniently available and willing to participate in this study were selected.

3.4.3.3 Inclusion criteria

The inclusion criteria for the study consisted of adults aged between 18 years and 65 years as they were able to give their own consent. They had a confirmed diagnosis of a severe mental illness (severe depression, schizophrenia, bipolar affective disorder, schizoaffective disorder), which was diagnosed by a psychiatrist as these conditions have been found to be chronic and enduring and may significantly affect a person's ability to function (Whiteford et al 2013:1579). The participants were mentally stable and not hospitalised at the time the study was conducted. Being mentally stable was measured by the participants having not been admitted into an acute psychiatric facility in the previous 12 months. The participants had also resided in a rural area of the northern region of New South Wales for a period of longer than six months so that they were familiar with mental health services in their local area and had established some form of a social network.

3.4.3.4 Exclusion criteria

Participants who were younger than 18 years, who were not mentally stable, who had been hospitalised within the last 12 months, who were not living in a rural area, or who had lived in a rural area for less than 6 months and did not have a diagnosis by a psychiatrist of a severe mental illness, were excluded from this study.

3.4.4 Data collection

Prior to the commencement of data collection the researcher obtained all the necessary permissions and informed consent from stakeholders (Refer to Section 3.7).

The data collection process is directly related to sampling. The researcher collects data directly from the identified sample population. The data gathered from the sample can either be direct or indirect. Direct data includes recordable spoken or written words and observable actions. Indirect data are data sources that were previously collected by someone else, such as documents or photographs (Schneider et al 2013:127).

Potential participants for the study responded to flyers (Refer to Annexure A) and participant information (Refer to Annexure H) that provided a brief description of the study, and contact information for the researcher. Potential participants were also recruited with the assistance of local mental health services. The researcher contacted the managers of the mental health services in the northern region of New South Wales and asked for assistance with the recruitment of study participants. The service managers informed case managers within their services who compiled a list of potential participants for the researcher to contact. The potential participants gave their consent to be contacted by the researcher. The researcher also contacted clubhouses, which are informal places where people living with mental illnesses like to gather and participate in social activities, to locate potential participants. Once potential participants were identified, they were screened for their eligibility for the study. Participants who met the inclusion criteria were asked to participate in the study. Their contact details were confirmed and an interview was scheduled. The researcher ensured diversity by selecting research participants who differed in their ages, genders, geographic locations, socio-economic statuses, and ethnical backgrounds.

Data was collected through face-to-face individual semi-structured interviews, field notes, and a reflective journal. Qualitative studies often make use of semi-structured interviews in which pre-determined topics and open-ended questions are laid out in an interview schedule. The interview schedule or topic guide (Refer to Annexure B) will list areas or questions to be covered with each participant (Creswell 2014:194; Polit & Beck 2012:537). Having the interviews face-to-face, the researcher was able to probe and investigate hidden views and experiences. The researcher was also able to observe

body language and eye contact and thus interpret what was being said. This also promoted a conversational tone during the interview and encouraged two-way interactions between the participant and the researcher where the participant was able to question the researcher (Creswell 2013:166; Yin 2011:134). Data was collected over a period of six months (April 2015 to September 2015) until data saturation was reached.

Most of the interviews were conducted at the participant's home with one interview carried out at the local mental health service. The interviews were conducted where each participant felt most comfortable. The researcher chose participants who were information rich and willing to share their experiences so that the researcher could generate data that was relevant to the study. The researcher conducted the interviews in English, and each interview lasted approximately 45 minutes. Data saturation was reached after 10 interviews, and 2 additional interviews were conducted after data saturation had been reached. The researcher, therefore, conducted interviews with 12 participants excluding those interviewed for the pilot study.

3.4.4.1 The data collection process

The different methods of data collection used in the present study will be discussed below. These included the pilot study, interviews, field notes, and the reflective journal.

a) Pilot study

A pilot study is a small scale study or trial run in preparation for the main study. The aim of the pilot study is to test the data collection instrument and assess the feasibility of the study (Polit & Beck 2012:195). The researcher interviewed 2 participants who met the inclusion criteria and their results were not included in the study. The pilot study allowed the researcher to pre-test the data collection tool and therefore refine the interview guide by clarifying some of the questions. For example, the researcher discovered that the question relating to other people involved in the mental health consumer's journey of seeking help was unclear, and this was modified. The pilot study also afforded the researcher the opportunity to practice her interviewing skills and become comfortable with the audio-recording device.

b) Interviews

The researcher conducted the semi-structured interviews and she was thus the primary instrument for data collection (Creswell 2013:45; Hissong et al 2015:105). The researcher made use of open-ended questions in order to gain a better understanding of mental health consumers' experiences of utilising mental health services and the influence that their social networks and social support have on these experiences. The use of open-ended questions rather than closed questions allowed the participants to answer in their own words rather than limit their responses to one-word answers (Yin 2011:135). The flexibility of the interview questions also allowed for the participants to share their experiences. The role of the interviewer was to encourage the participants to talk freely about the topics on the topic guide by sharing stories in their own words (Polit & Beck 2012:537). Semi-structured interviews have the flexibility necessary to follow issues raised by the participants that the researcher may have not anticipated (Creswell 2013:173; Yin 2011:134). Data collection continued until data saturation was reached.

Liamputtong (2013:71) and Schneider et al (2013:130-131) discuss the advantages and limitations of interviews:

Advantages of interviews

1. Interviews can explore research topics when little is known about them or if the issues are complex.
2. Interviews allow researchers to explore the perceptions of the participants and how they give meaning to their experiences.
3. Interviews allow for the words of the participants to be captured which means the researcher can focus on the issues important to the participants.
4. During interviews, researchers are able to observe and record non-verbal behaviour.
5. The process of interviewing is based on existing skill of conversation and communication, which most people possess.
6. Interviews require minimal specialist equipment such as a tape recorder or dictaphone.

Disadvantages of interviews

1. Interviews are time-consuming, particularly with regards to transcription and data analysis.

2. It may be difficult for novice researchers to elicit in-depth information from participants, affecting the quality of the data collected.
3. Interviews can be demanding and exhausting for the researchers.
4. There is potential for an imbalance of power between the researcher and the participants.

The researcher used semi-structured interviews as a means of data collection because little is known about the role of social networks and social support as it pertains to the use of mental health services by mental health consumers in rural New South Wales. The researcher was also able to understand how the participants gave meaning to their experiences of social networks and social support.

- **Researcher as a key instrument**

In qualitative research, the researcher is often called the “tool” or “instrument” for data collection. This means that all interpretations and observations are filtered through the researcher who has their own values and assumptions (Creswell 2014:185; Hissong et al 2015:105; Polit & Beck 2012:487). Thus, in this study the researcher was the key instrument of data collection through interviews with the participants. The researcher made use of both verbal and non-verbal communication techniques.

- **The interview process**

At the start of the interview, the researcher again provided an explanation of the purpose of the study and a description of how confidentiality and anonymity will be maintained. Next, the informed consent form was reviewed and signed. The researcher informed the participants about the ethical clearance and permissions obtained. The participants were provided with information about their right to withdraw from the study at any point during the research. The researcher asked the participant to choose a pseudonym in order to protect their identity during the study (anonymity). With the permission of the participants, the interviews were audio-recorded. At the end of each interview, field notes were taken to record contextual information such as non-verbal expressions so that the richness of the interview could be captured (Creswell 2014:196). A reflective journal was kept to take note of the researcher's own assumptions and presuppositions. After the interviews had been completed, they were

transcribed and field notes were consulted. The researcher made use of observational field notes and reflective notes.

c) *Field notes*

Field notes are notes made by researchers to record unstructured observations in the field and the interpretation of those observations. Field notes are both descriptive and reflective (Liamputtong 2013:30). Descriptive or observational notes provide descriptions of events and conversations that were observed in a particular context as objectively as possible. Reflective notes document a researcher's thoughts, feelings, reflections and personal experiences while in the field. During the study the researcher made use of methodologic notes, theoretical/analytical notes, and personal notes (Polit & Beck 2012:58-549):

- **Methodologic notes**

Methodologic notes are reflections about methods and strategies used in observation. They may provide instructions about how further observations will be made in the field (Polit & Beck 2012:549). During this study, the researcher made use of unstructured observation during the interviews to describe events and behaviours as they occurred.

- **Theoretical/analytical notes**

A researcher records their thoughts about how to make sense of what is going on in theoretical/analytical notes. Theoretical/analytical notes often serve as a starting point for data analysis (Polit & Beck 2012:549). During this study, the researcher kept notes of the interpretations of the behaviours that were observed. This assisted in the process of data analysis.

- **Personal notes**

Personal notes are a record of the researcher's own feelings in the field (Polit & Beck 2012:549). The researcher kept a reflective journal which is discussed below.

d) *Reflective journal*

Reflective notes are those notes that the researcher made shortly after the interview. They reflected on thoughts and feelings brought up during the interviews and things that challenged the researcher's assumptions (Liamputtong 2013:30; Polit & Beck 2012:546-547). Reflective notes are contained within a reflective journal and may also record a researcher's ethical dilemma. Reflective notes allow a researcher to reflect on how their thoughts and feelings are influencing what is observed (Polit & Beck 2012:549). The researcher kept a reflective journal throughout the duration of the study. The researcher recorded her feelings, thoughts and assumptions before the commencement of data collection and during the study. The researcher consistently reflected on how she may be influencing the study and the interpretation of the findings (Refer to Annexure K for an excerpt of the reflective journal). Data from the reflective journal was analysed and incorporated with the study findings.

3.5 DATA ANALYSIS

All the recorded interviews were transcribed verbatim by the researcher and accuracy was checked by listening to the audio recordings several times until the researcher was satisfied that the transcription was accurate. Transcripts and field notes were read and re-read numerous times to allow the researcher to be fully immersed in the data (Liamputtong 2013:241). Data collection and analysis occurred simultaneous during the course of the study (Creswell 2014:195).

All the data collected (interviews, field notes and reflections from reflective journal) was analysed manually since working with paper transcripts is central to qualitative research. It allowed the researcher to maintain intimacy with the original data (Polit & Beck 2012:561).

The researcher firstly made use of open coding in order to organise the raw data. Open coding involved the researcher approaching the raw data without any preconceived ideas as to how to code the data (Polit & Beck 2012:569; Tappen 2011:367). The researcher then moved onto thematic analysis in order to analyse data. Thematic analysis is a more common type of data analysis in qualitative research. It involves

identifying themes through the reading and re-reading of the raw data (Liamputtong 2013:249-250; Liamputtong & Serry 2013:375).

The researcher made use of Liamputtong's (2013:245) eight-step method summarised from Bryman (2012) to code the data (Refer to Annexure D for coding protocol). The researcher commenced coding while the data was being collected to give her a better understanding of the data. The interview transcripts, field notes and reflective journal were read without making any notes or attempting to interpret the data. After reading the data, a few notes were made regarding what appeared to be important or significant. The data was then read again, but this time the researcher made marginal notes about significant observations or categories that emerged. The researcher made use of keywords expressed by the participants, or gave names to themes in the data (this is coding). The researcher then generated an index of terms that assisted with the interpretation of the data. The codes were reviewed and if there were two or more words or phrases relating to the same issue, one of them was deleted. The researcher then considered theoretical notions as it related to the codes and data and outlined connections between concepts and categories that were being generated. The researcher should thought about how these concepts related to the existing literature. A large number of codes were generated during the early stages of data analysis. The researcher looked closely at the data to see if it could be coded differently. As part of thematic analysis, the researcher had to find links between various codes to determine what the participants were saying as a group (Liamputtong 2013:249-250; Liamputtong & Serry 2013:375). The researcher made use of an independent coder during data analysis to ensure objectivity and a consensus discussion was held to ensure that the themes identified correlated with the data collected (Refer to Annexure J for a copy of the letter from the independent coder).

3.6 MEASURES TO ENSURE TRUSTWORTHINESS

Polit and Beck (2012:584-585) discuss Lincoln and Guba's (1985) framework for maintaining the scientific rigour of a qualitative inquiry. The four criteria Lincoln and Guba (1985) outline are credibility, dependability, conformability, and transferability. In 1994, Lincoln and Guba added authenticity as their fifth criterion.

3.6.1 Credibility

Credibility refers to the truth of the research findings and the interpretation of thereof. It answers the question of whether the research findings can be regarded as truthful (Liamputtong 2013:26). Credibility is viewed as the primary goal of qualitative inquiry (Polit & Beck 2012:584). During the study, credibility was maintained through triangulation, member-checking, and peer debriefing or review. Triangulation is when researchers make use of multiple data sources in order to provide corroborating evidence (Creswell 2014:251; Liamputtong 2013:30-31; Polit & Beck 2012:590). During the study, the researcher sought to gather data from the research participants using the semi-structured interviews, observations of the research participants during the interviews since the interviews were audio-recorded, and through the field notes and reflective journal.

Member checking involves checking the findings with the participants to ensure their views have been captured accurately (Creswell 2013:201; Liamputtong 2013:32; Polit & Beck 2012:591). During the study, the researcher checked the accuracy of the information by summarising the main points at the end of the interview and checking this with the participants. The researcher checked the accuracy of the transcripts after the interviews had been transcribed and also confirmed the accuracy of initial themes with the research participants if this was required.

Peer debriefing involves allowing peers to explore and review various aspects of the research. This permits the researcher to expose the research to the questions of others in the field (Creswell 2014:202; Polit & Beck 2012:594). For the study, the researcher submitted a sample of transcripts to be independently reviewed by the supervisor and another sample was reviewed by an experienced researcher who recently completed her PhD on mental health consumers. The researcher also made use of an independent coder during data analysis (Refer to Annexure J).

3.6.2 Dependability

Dependability refers to the ability to show that the findings are consistent and could be repeated if the study were replicated (Liamputtong 2013:26; Polit & Beck 2012:585). An independent coder was used during data analysis to ensure objectivity (Refer to

Annexure J). A consensus discussion took place between the researcher and the independent coder to ensure themes identified correlated with the data collected. Data can be re-coded to compare the similarities of the findings. The researcher provided thick description of the methodology to allow readers to make decisions around the transferability of the research findings (Creswell 2013:252). The researcher also kept an audit trail and the data was locked away in a secure cabinet which will only be accessible to the researcher after the completion of the study.

3.6.3 Confirmability

Confirmability refers to the objectivity and neutrality of the study. In other words, there needs to be congruency between the information provided by the participants and the findings of the study. The data should accurately represent the information provided by the participants and not be influenced by the researcher's bias or motivations (Liamputtong 2013:27; Polit & Beck 2012:585). During the study, confirmability was maintained through establishing an audit trail and through reflexivity. An audit trail is a transparent and systematic account of the research process from start to finish. This includes the raw data collected, field notes, and descriptions and any journals kept. An audit trail would enable an external auditor to come to conclusions about the data (Creswell 2013:252; Polit & Beck 2012:591). An audit trail will be kept for the study. This will include recruitment materials, interview guides, field notes, reflective journal, and interview transcripts. The raw data will be kept under lock and key by the researcher for 15 years.

Reflexivity is concerned with the honesty and integrity of the researcher conducting the study. The researcher needs to be aware that their personal background, experiences and bias may shape the direction of the study and the research process (Creswell 2013:215; Liamputtong 2013:29-30; Polit & Beck 2012:589). During the study, a reflective journal was kept to enable the researcher to record her suppositions and how these may have been influencing the direction of the study and the interpretation of the research findings (Refer to Annexure K).

3.6.4 Transferability

Transferability is the extent to which the findings of a study can be transferred or applied to another context (Liamputtong 2013:27; Polit & Beck 2012:585). The researcher provided thick descriptions of the context, methodology and findings in this study. The researcher also made use of purposive sampling and literature control. Verbatim transcriptions have been included as an addendum in the study (Refer to Annexure I).

3.6.5 Authenticity

Authenticity is concerned with accurately reflecting the tone of the participants' lives as they are lived. According to Polit and Beck (2012:540), authenticity refers to providing a true report of the different viewpoints of reality from participants' perspectives. Authenticity was maintained during the study by quoting the research participants verbatim in the research findings section of the study.

3.7 ETHICAL CONSIDERATIONS

The section below outlines how permission to conduct the study was obtained, the process of gaining consent, the ethical principles adhered to, and how confidentiality and anonymity was maintained.

3.7.1 Permission

The researcher obtained ethical clearance from the Higher Degrees Committee of the Department of Health Studies at the University of South Africa (REC-012714-039) (Refer to Annexure E). Since this study was conducted in Australia, the researcher was required to submit an additional research proposal to the Hunter New England Ethics Committee. The researcher obtained permission from the Hunter New England Ethics Committee to proceed with data collection at all mental health service sites in the northern region of New South Wales (15/02/18/4.09) (Refer to Annexure F).

After permission was obtained, the researcher wrote a letter to the service managers of local mental health services and club houses with information about the study. In the letter the researcher requested assistance with the recruitment of potential participants

and permission to place information about the study in waiting areas (Refer to Annexure G).

3.7.2 Informed consent

Informed consent refers to the process whereby participants have been given enough information about a proposed study that they have the ability to consent or decline participation in the study (Polit & Beck 2012:157).

The researcher made use of the steps outlined by Polit and Beck (2012:158) to obtain informed consent from the prospective participants. The researcher ensured that the participants understood the difference between research and treatment; they were made aware that they would not receive treatment from the researcher as a result of participating in the study. Since the participants were part of a vulnerable population, the researcher made sure that the participants were mentally stable and able to provide consent. The researcher was able to assess whether a participant was mentally stable during a telephonic conversation. The participants participated voluntarily in the study. The researcher did not exercise any coercion in order to make the participants take part in the study.

The researcher informed participants of the research goals in terms that they were able to understand. She advised the participants that data would be collected through face-to-face interviews and that notes would be taken during the interviews. Each interview would be between 45 and 60 minutes long. The researcher informed the participants that the interviews would be audio-recorded with their permission. The participants were informed that the study formed part of the researcher's partial fulfilment of the Masters in Public Health programme through the University of South Africa (UNISA).

The researcher advised the participants that they may be asked to recall events they may find distressing and the researcher would make referrals to local mental health services if further support is required. No participants became distressed during the interviews, so this was not required. She advised participants that there would be no immediate direct benefits to them as a result of participating in the study. However it is anticipated that the information gained would improve service delivery for rural mental health consumers in the future. The researcher advised that no reimbursements would

be paid to the participants as a result of participating in the study. She assured prospective participants that their privacy and anonymity would be maintained. The participants were asked to select a pseudonym to maintain anonymity. The researcher informed the participants that participation in the study was strictly voluntary and that failure to participate would not result in any penalties or loss of benefits. The researcher also advised the participants that they have the right to withdraw from the study at any time and have the right to withhold information they do not wish to disclose. Finally, the researcher provided the participants with her contact details should they have any further questions. The researcher then asked the participants to sign the informed consent form (Refer to Annexure C) if they were in agreement with the above.

3.7.3 Ethical principles

Since World War II, there has been the potential for mistreatment of research participants. As a result of this, the Belmont Report (1979) outlines the three ethical principles that must be adhered to when conducting research. These are beneficence, respect for human dignity, and justice. Polit and Beck (2012:152-156) and Tappen (2011:173-179) discuss these three broad ethical principles.

3.7.3.1 Principle of beneficence

Beneficence is the duty of researchers to minimise harm (nonmaleficence) and maximise benefits for research participants (Polit & Beck 2012:153; Tappen 2011:174). During the study, although the research participants did not receive immediate benefit from their participation in the study, it is anticipated that the findings from the study will help improve service delivery for them and other rural mental health consumers in the future. The researcher showed great sensitivity when asking questions during the interviews so as not to cause the participants any unnecessary distress. None of the participants became distressed during the course of the interviews, and so, there was no need for a referral to counseling for any of the participants.

3.7.3.2 Principle of respect for human dignity

Respect for human dignity is concerned with treating research participants as autonomous agents who are able to exercise self-determination and capable of

controlling their actions (Polit & Beck 2012:154; Tappen 2011:174). The researcher made sure that the participants understood their participation in the study was entirely voluntary and that they could withdraw from the study at any time without fear of loss of benefits. None of the participants withdrew from the study. To minimise the risk of coercion, no reimbursements were offered to the research participants. The researcher also disclosed all the details about the study as part of gaining informed consent from the participants.

3.7.3.3 *Principle of justice*

Justice is concerned with the participants' right to fair treatment and their right to privacy (Polit & Beck 2012:155; Tappen 2011:174). The researcher treated all the participants fairly and without prejudice. She informed the participants that their personal information would be kept in the strictest confidence and that only the researcher, her supervisor and an independent coder would have access to the data and they were asked to sign a confidentiality agreement. The participants were also requested to select a pseudonym to protect their anonymity further.

All documents and data sources, including consent forms, audiotapes, transcripts, and portable disc drives were locked in a secure filing cabinet in the researcher's home office and will be kept there for 15 years. It will only be accessible to the researcher. Each participant selected a pseudonym that further protected their identity (anonymity). Confidentiality was further ensured as only the researcher, the independent coder, and the supervisor would have access to the data.

3.8 CHAPTER SUMMARY

This chapter discussed the research design and methodology, including the setting, population, sample, sampling, data collection, data analysis, measures to ensure trustworthiness, and ethical considerations.

Chapter 4 describes the data analysis and results.

CHAPTER 4

DATA ANALYSIS AND RESULTS

“I have been deeply humbled by the fact that people have sat with me and trusted me with their stories. I count it an incredible privilege and want to do their stories justice in this research”.

(extract from reflective journal: 12/06/2015)

4.1 INTRODUCTION

Chapter 3 discussed the research design and methodology. As part of this, the data collection process was described in detail. Chapter 4 provides the data analysis, interpretation, and presentation of the results. The main aim of the study was to enhance the understanding of the role that social networks and social support have on mental health service utilisation by mental health consumers in rural New South Wales. The objectives of the study were to establish what social networks mental health consumers make use of to explore and describe the influence of social networks in the decision-making process to utilise mental health services. It also explored and explained the perceived support that social networks provide to mental health consumers to make recommendations for health care workers to enhance the role of social networks in the utilisation of mental health service utilisation.

Throughout the research process, the researcher identified that there is limited literature available on the research topic, especially with regards to recent sources written within the last five years. This was discussed in detail in Chapter 2. The researcher also used the services of the subject librarian for the College of Health Studies together with the assistance of the supervisor. The subject librarian and supervisor both encountered the same challenge as the researcher in terms of sourcing relevant and recent sources pertaining to the research topic.

As such, the researcher also used sources dating from 1995 to 2015. Recent sources that were identified through the Ebsco Host database retrieved two articles (Anderson, Laxhman & Priebe 2015:27; Rivlin, Hawton, Marzano & Fazel 2013:1). Upon examination, the researcher determined these were not applicable or relevant to

support the study findings. The researcher endeavoured to use recent sources where possible and was fortunate to locate a few studies published in early 2016 and late 2015 which have recently become available. These have been used in this chapter.

Due to limited sources, this study will make a significant contribution to add updated knowledge and information in the area of social support and social networks and the impact it has on mental health service utilisation by mental health consumers.

4.2 DATA MANAGEMENT

Data management in qualitative research involves converting large amounts of data into smaller, more manageable segments (Polit & Beck 2012:515). For the present study, data management will refer to data collection and data analysis. During the research, data was collected through individual semi-structured interviews. These interviews were audio-recorded and then transcribed verbatim with the permission of the participants. To protect the participants' privacy, confidentiality, and anonymity, the researcher used pseudonyms and not the participants' real names. Each audio file was labelled with the date of the interview, the number of the interview, and the pseudonym. For example 20/04/2015, Interview 3, Fred. The audio recordings, transcripts and demographical forms were stored in a locked cabinet in the researcher's home office that is only accessible to the researcher.

The researcher made use of open coding in order to organise the raw data and moved onto thematic analysis to analyse the data. During the process of data collection initial themes began to emerge. The researcher continued to collect data until data saturation had occurred. Initially, the researcher completed ten interviews but then conducted two more interviews to ensure that data saturation had truly occurred. Data collection was completed over a period of 6 months from April 2015 to September 2015. During the process of data analysis the researcher made use of an independent coder to enhance the credibility of the study, and a consensus discussion was held to review themes and categories (Refer to Annexure J for the report from independent coder). Four themes, sixteen categories, and four sub-categories were identified (Refer to Table 4.2). A conceptual map also emerged from the participants' recorded experiences (Refer to Figure 4.1).

4.3 PARTICIPANTS' PROFILE

Twelve participants took part in the research. Six of the twelve participants were male (50%) and six participants were female (50%). Most of the participants were single (66.7%). Three participants were divorced (25%) and one participant was married (8.3%). The participants' ages ranged from 28 years to 62 years. The mean age was 43.6 years. Most of the participants were unemployed (75%) while three (25%) were employed part-time. Seven participants had completed tertiary education (58.3%), two completed grade 12 (16.7%), one completed grade 8 (8.3%), one completed grade 10 (8.3%) and one completed grade 11 (8.3%). The most common diagnoses were Schizophrenia (33.3%) and Bipolar Affective Disorder (33.3%). These were closely followed by Schizoaffective Disorder (25%), and one participant had a diagnosis of Major Depressive Disorder (8.3%). Participants' stay in a rural area ranged from one year to 44 years. The mean stay was 22 years. The majority of the participants lived alone (91.6%) while the one married participant (8.3%) lived with her husband and four children. Table 4.1 summarises the participants' demographic details.

Table 4.1: Participants' demographic details

PARTICIPANT	AGE	GENDER	MARITAL STATUS	EMPLOYMENT STATUS	LEVEL OF EDUCATION	DIAGNOSIS	LENGTH OF STAY IN RURAL AREA
1	40 years	Male	Divorced	Part-time employment	Tertiary	Schizophrenia	10 years
2	33 years	Male	Single	Unemployed	Tertiary	Schizophrenia	7 years
3	51 years	Female	Single	Unemployed	Tertiary	Schizoaffective Disorder	44 years
4	30 years	Male	Single	Part-time employment	Tertiary	Bipolar Affective Disorder	30 years
5	43 years	Male	Single	Unemployed	Tertiary	Major Depressive Disorder	9 years
6	60 years	Female	Single	Unemployed	Tertiary	Schizoaffective Disorder	1 year

PARTICIPANT	AGE	GENDER	MARITAL STATUS	EMPLOYMENT STATUS	LEVEL OF EDUCATION	DIAGNOSIS	LENGTH OF STAY IN RURAL AREA
7	28 years	Female	Married	Unemployed	Grade 12	Bipolar Affective Disorder	1 year
8	57 years	Female	Divorced	Unemployed	Grade 8	Schizoaffective Disorder	42 years
9	62 years	Female	Divorced	Unemployed	Grade 10	Bipolar Affective Disorder	33 years
10	54 years	Male	Single	Unemployed	Grade 11	Schizophrenia	54 years
11	28 years	Female	Single	Unemployed	Tertiary	Bipolar Affective Disorder	24 years
12	37 years	Male	Single	Part-time employment	Grade 12	Schizophrenia	10 years

4.4 FINDINGS

Four themes, sixteen categories, and four sub-categories were identified during the process of data analysis (Refer to Table 4.2).

Table 4.2: Summary of themes, categories and sub-categories

THEME	CATEGORY	SUB-CATEGORY
Theme 1: Relationships	1.1 Relationship with partner 1.2 Relationship with children 1.3 Relationship with health professionals 1.4 Relationship with friends	
Theme 2: Living with mental illness	2.1 Symptoms of mental illness	2.1.1 First person to notice symptoms

THEME	CATEGORY	SUB-CATEGORY
	2.2 Medication	
	2.3 Attitudes towards living with mental illness	2.3.1 Family's attitude towards mental illness 2.3.2 Consumers' attitude towards mental illness 2.3.3 Society's attitude towards mental illness
	2.4 Hospital admission	
	2.5 Influence to use mental health services	
	2.6 Physical health impacting on mental well-being	
Theme 3: Social support	3.1 Emotional support 3.2 Physical support 3.3 Financial support 3.4 Support from mental health services	
Theme 4: Social networks	4.1 Contact with others 4.2 Methods of communicating	

4.5 THEME 1: RELATIONSHIPS

The theme of relationships was the first theme to emerge during data analysis. The participants viewed relationships in different categories. These included relationships

with their partner, relationships with their children, relationships with health professionals, and relationships with friends. In general, relationships were linked to a sense of belonging and being connected to others.

One participant described relationships as having someone to talk to and feeling loved by her children:

“Aah... just more company... um... I got- my kids always say “I love you mum” at the end of every phone conversation and all that”. (Participant #8)

Another participant described the ingredients required for companionship:

“Just being around people who wanna do- who are all there for the same reason- you build a friendship”. (Participant #5)

Still another participant described relationships as family and friends caring for him and having his best interest at heart:

“...That’s how families are and friends are; they want the best for you.” (Participant #1)

Relationships were also described as having people you can call on if you need any assistance:

“I’ve had friends over the years that have helped. A friend here and there... seems to have always been someone there I could ring”. (Participant #8)

A participant appreciated it when he experienced freedom in his relationships by being comfortable with another person and having the freedom to make his own choices:

“Just establishing friendships and just you know, not rushing into things or not being bound by people. You know, and not being um controlling in a relationship whether it’s a bloke or a female, like decide together or let the other person decide or whatever; what we’re going to do or what, what we would like to see or um yeah and then communicating like talking...” (Participant #1)

Demir and Weitekamp (2007:181) found that quality friendships were able to enhance happiness and general mental well-being. Having supportive relationships with friends, family and significant others also improves general psychological well-being and the sense of belonging and connectedness (Kawachi & Berkman 2001:461).

The four different types of relationships described by the participants (relationships with partner, relationships with children, relationships with health professionals, and relationship with friends) are discussed below in more detail.

4.5.1 Relationship with partner

Ten of the twelve participants were single at the time of the study. As a result, the participants drew on their past experiences of being in previous relationships. More than half of the participants (7 out of 12) were divorced or had experienced a broken engagement. The participants attributed their relationship breakdowns to their mental illness and the inability of their partners to cope with their mental illness. Participants, therefore, identified intimate relationship challenges.

One participant acknowledged the difficulty of having intimate relationships when living with a mental illness as he believed women were not interested in him because he was living with a mental illness. He stated:

“She eventually gave me- booted me out...a lot of women aren’t particularly interested in you when you’ve got mental illness”. (Participant #10)

Another participant discussed how other priorities, such as responsibilities towards family, would overtake the need for an intimate relationship with a partner:

“I have a friend um who lives on the other side of town kinda like a boyfriend. He has a mother who’s 91 almost. And she ah, requires all his attention now so he doesn’t come over that much. And that’s really sad for me cause we were sexual partners”. (Participant #9)

The participant below described how her husband had ended their marriage following her hospital admission to an acute mental health unit and asked her to leave the family home:

“Everything had fallen apart in my marriage by then... my ex kicked me out the house when I come home from [B hospital] ... and said he didn’t want me there... so I took that to heart. That was the end of everything then. ah”. (Participant #8)

Another participant discussed how he found his intimate relationship with his wife difficult as he experienced his wife as controlling. Now, as a single person, he has opportunities to explore relationships with others:

“I think having a bit of freedom in my relationship and being ...living by myself. I can sort of see who I want to see, whereas I couldn’t do that in my relationship when I was married. I was sort of bound by my wife a little bit. She was a little bit more controlling. She tried to look after me by controlling me and not wanting me to go and see people or coming home after I went to a meeting or something and not going out to coffee or something after it. So I was a bit controlled and I haven’t got that anymore”. (Participant #1)

Baker and Proctor (2015:97) conducted a qualitative study among adults living with mental illness at a local community mental health centre. The participants described lost relationships as a possible cause for their mental illness and cited failed relationships as the most significant loss they had endured as a result of their mental illness. Participants mentioned the loss of intimate relationships (partner/spouse) through death or divorce, and the loss of relationships with children, friends and family. The findings of Baker and Procter (2015:97) are similar to the conclusions of this present study, where the majority of the participants attribute their relationships breaking down as a result of their mental illness.

A participant described how she was violent and abusive in her relationship with her husband as a result of the symptoms of mental illness:

“...Lost control of my relationship. Lost control of me... Wake up and do the same routine shit. Bitch about it, cry about it, scream about it. Bash the husband. Just totally flip out!” (Participant #7)

On the other hand, one of the participant's husband was the one violent towards her:

“... I was very concerned about the kids... cause I- at that point I was fearful of my husband”. (Participant #8)

Participant #7 and participant #8 highlighted an important dynamic. Sometimes the person living with the mental illness is the abuser (Participant #7) and sometimes the person living with mental illness is the abused (Participant #8).

Nathanson, Shorey, Tirone and Rhatigan (2012:59) define intimate partner violence as acts of physical, sexual and psychological aggression directed towards a romantic partner. Intimate partner violence is associated with perceived poor mental health. Intimate partner violence places women at risk of developing a mental health disorder (Dillon, Hussain, Loxton & Rahman 2013:1; Nathanson et al 2012:59). Women who experience intimate partner violence report higher rates of mental disorders (Depression, Post-Traumatic Stress Disorder and Substance Dependence) when compared to the general population (Nathanson et al 2012:64; Trevillion, Oram, Feder & Howard 2012:1). Women living with a mental illness are also more vulnerable to experiencing intimate partner violence (Friedman & Loue 2007:474-475). This is demonstrated by Participant #8 who developed her mental illness during the course of her marriage where she was experiencing intimate partner violence. Friedman and Loue (2007:471), during their systematic review of literature, found that a high proportion of women living with a mental illness may assault their intimate partners as demonstrated by Participant #7 who was the perpetrator of the abuse in her relationship with her husband.

Coker, Smith, Thompson, McKeown, Bethea and Davis (2002:465) conducted a study among women experiencing intimate partner violence to assess the impact this had on their mental health. These authors found that social support reduced the impact of the abuse on the women and resulted in the women reporting lower scores of poor mental health with regards to depression, anxiety and suicidal ideation. Health professionals

can play an important role in identifying intimate partner violence and facilitating social support. They also form part of the social support networks of women experiencing intimate partner violence. This is illustrated by a participant who shows how mental health services were instrumental in helping her move away from her husband who was violent towards her:

“[Mental health services] well ah took me out of a violent situation... um... I I felt like I had someone to talk to after all that period of years cause I never told anyone about what was going on at home... until then”. (Participant #8)

A participant discussed how her engagement broke off and how the stress of the broken engagement brought on symptoms of depression:

“Ahh I was under a lot of stress; I had an engagement split up... I got engaged to my boss and I couldn’t keep the job because I was engaged to my boss and then he broke off the engagement. So that was a lot of stress; as you know, stress can bring on depression”. (Participant #3)

The above participants mainly discussed their intimate relationship challenges, which included stigma, rejection, violence and abuse. Only one of the participants expressed their desire to be in an intimate relationship. This participant stated:

“Ahh I want a girlfriend. That’d be good; that’d be better. Yeah...” (Participant #2)

Participant #2’s desire to have a girlfriend was expressed twice during the interview:

“Aww have a girlfriend”. (Participant #2)

When questioned by the researcher, this participant expressed that having a girlfriend:

“...would be better than having social networks...oh because; because you’d look out for each other I suppose”. (Participant #2)

In Participant #2's view, having a girlfriend would provide him with more support than he was presently experiencing. It appears as if a girlfriend would form a significant part of his social network and therefore be an important part of his social support.

Another participant expressed:

"I've only been married once but I've had a couple of fiancé's and I've had trouble with men. Picked the wrong ones you know? Pick ones that become um leeches". (Participant #9)

Participant #9 may have felt that her judgment have been clouded when it came to choosing intimate partners.

Unlike this study, Padgett, Henwood, Abrams and Drake (2008:336) in their study amongst persons living with severe mental illness, found that responses from participants varied. There were those participants who had a strong desire to be in intimate relationships as they did not want to "die alone". There were also participants who did not prioritise intimate relationships as they believed they needed to "get themselves together first". Other participants were afraid to pursue intimate relationships due to past experiences. This may have also been the case with the majority of the participants in the present study as most experienced rejection, leaving them vulnerable and cautious towards relationships.

Ritsher, Coursey and Farrell (1997:1273) found that women, more than men, identified personal relationships as being the most important aspect to them. Although women acknowledged that having a severe mental illness had a negative impact on their lives, they reported normal concerns rather than concerns that were illness related. In general, women reported a better quality of their personal relationships compared to men. The present study did not support Ritsher et al (1997:1273), as there generally was no difference between the quality of relationships reported by the male and female participants. However, the female participants in the present study were the only participants that had children. The relationship the participants had with their children is further discussed below.

4.5.2 Relationship with children

Children were supportive or resentful and unsympathetic towards their parent's illness. This influenced the relationship participants had with their children by creating closeness or distance. The older the age of the children of the participants, the more strained or troubled the relationship seemed to be. The younger the age of the children, the more positive the relationship.

Only three of the twelve participants had children (Participants #7, #8 and #9).

The children of the participants may have had to take on the caring role for their parents, especially if they were young when their parent became unwell, as illustrated by the following quote:

"Well my daughter has been my best and greatest help... she was only about 16 when I first became ill. But she really helped me a lot and still does". (Participant #8)

When a child has a parent living with a mental illness, it places them at greater risk of having lower social, psychological and physical health compared to a child who lives with a parent without a mental illness (Ruepert & Maybery 2007:362-363). This was clearly illustrated by this participant when she discussed her daughter:

"It's got to the point now where she doesn't want to be so involved [in my life and mental illness] because she's not feeling all that well herself". (Participant #8)

Family members may experience stigma on account of their relative living with mental illness (Karnieli-Miller, Perlick, Nelson, Mattias, Corrigan & Roe 2013:254). As a result of this stigma, family members may experience rejection, blame and avoidance by others. To minimise the effects of stigma, families learn to be selective about the information they disclose to others about their relative living with mental illness (Karnieli-Miller et al 2013:254).

Caring for a parent with a mental illness may also come with a lot of resentment on the part of the children:

“My kids can be quite cruel sometimes... They can be pretty harsh sometimes and not very sympathetic. Um... so that hurts me cause I love them very much”. (Participant #8)

Children were a motivation for one of the participants to get treatment for her mental illness. The children provided valuable social support that enabled this participant to access the help she required. They were also a motivator for this participant to keep living. This participant stated about her children:

“I’ll honestly say they’re the reason I’m alive”. (Participant #7)

Aldridge (2006:81) found that children often take on emotional care responsibilities for their parent living with a mental illness. Children provide critical support, especially when the mental health of parents takes a downturn. Children are frequently the first point of contact for episodes such as self-harming (Aldridge 2006:81).

The participant further reiterated:

“Same as what I told every doctor I’ve spoken to. If it wasn’t for my children I would have committed suicide”. (Participant #7)

Children often took on the domestic responsibilities of the home as well as looking after younger siblings (Aldridge 2006:81; Ruepert & Maybery 2007:364). Children were also responsible for helping the participants in practical ways and organising their lives, as illustrated by the following quote:

“My daughter came down for a week or a bit over a week and got a whole lot of work done which I really appreciated”. (Participant #9)

Participants identified strained relationships with their children at times as a result of their living with mental illness and the acute episodes caused by mental illness:

“Well they had- they’ve lost patience with me really to be honest”. (Participant #9)

“...There’s a rift there between us sort of... not that there’s a dislike or anything... we like each other but um... when I got crook [sick] he seemed to pull away... and it’s never been the same since”. (Participant #8)

As stated before, the younger the age of the children of the participants, the more positive the relationship. The older the children of the participants were, the more strained the relationship appeared to be. The children of the participants seem to form a significant part of the participants’ social network and social support. However, as the children grow older, they become more resentful and although they still form part of the participants’ social network, they may not necessarily provide the participants with much social support.

Karp and Tanarugsachock (2000:6) conducted a qualitative study exploring how caregivers to a spouse, parent, child or sibling living with severe mental illness manage their emotions. These authors identified that initially, the caregivers experienced confusion because of the behaviours of their relative living with mental illness. After a diagnosis is provided, they experience feelings of hope and compassion. At a certain point the caregivers realise that the mental illness of their relative is permanent and they experience negative feelings of anger and resentment. This was the case for many of the children of the participants.

In a study by Murphy, Peters, Jackson and Wilkes (2011:3433), adult children of parents living with mental illness reported that their negative feelings towards their parents were because they felt they did not experience emotional bonding with their parents. Instead, they had to take on the parenting role and they experienced parental absence.

Children and young people under the age of 18 years who provide care, assistance and support to another family member (a parent living with a mental illness), have been described in the literature as ‘young carers’ (Becker 2007:25-26). These young carers form an important part of the social support of their relative living with mental illness (Becker 2007:26; Thomas, Stainton, Jackson, Cheung, Doubtfire & Webb 2003:36). As a result of their caring responsibilities, children may experience symptoms of depression, anxiety, and stress (Thomas et al 2003:40).

The children of two of the participants in the present study were once young carers. The children of one of the participants were presently young carers as they were under 18 years of age.

Ruepert and Maybery (2007:364) found that ongoing caring responsibilities on the part of the children often lead to caregiver strain. This is clearly illustrated by the participants' quotes above. These authors further identified that when children experienced caregiver strain, they were prone to withdraw, distance themselves, and have maladaptive coping strategies. The participants in the study relied on the relationship they had with mental health professionals to help them deal with some of the challenges with their children. The relationships with health professionals are discussed next.

4.5.3 Relationship with health professionals

The participants described their relationships with health professionals as either positive or negative. The majority of the participants described their relationships with health professionals in positive terms. In general, the participants expressed that health professionals created a safe space where participants felt accepted and cared for. Participants felt that relationships with health professionals were supportive and that health professionals were an important part of their social networks.

One participant identified that she appreciated relationships with health professionals where she felt accepted:

"I actually loved going to see a psychiatrist where I didn't feel judged, I felt supported and cared for". (Participant #6)

Another participant stated:

"Well [Health Professional A] just keeps an eye on me...and gives me somewhere to ring. [The community mental health team] gives me somewhere to ring... if I'm not feeling well... or if I'm feeling too well... when I get manic... then [Health Professional A] will notice that I'm not quite right... he keeps in contact with me...He's really good...I just find that it gives me a sense of security..." (Participant #8).

This participant had developed a trusting relationship with her case manager [Health Professional A] and knowing that Health Professional A was only a phone call away, gave her a sense of security.

This was also highlighted by the following participant who felt that it was reassuring to know his case worker was accessible and available to him and could be contacted by phone or email:

“... The case workers, um... they’d be my major contacts, major people that um...looked after- you know what monitored my medications... the case worker- I’ve had a lot of little things come up and just knowing she’s a phone call away or an email away just to get on track...” (Participant #5)

When asked about his experience with health professionals, Participant # 10 advised:

“They’ve been great. Like [Health Professional B’s] been fantastic”. (Participant #10)

Another participant related that:

“... Most professionals treat me with respect and that’s important”. (Participant #3)

Mental health consumers have identified respect as the most important ingredient in collaborating with health professionals (Goodwin & Happell 2007:612). Mental health consumers appreciate it when health professionals respect them and acknowledge the contribution they can make to their own care and treatment (Happell, Manias & Roper 2004:245).

One participant described how important it was for them that health professionals showed an interest in their well-being and the support they received from the nurses:

“... When I’m well and treated right on the medication I can understand where the nurses are coming from. So they’ve been there to give me medication; ask me

questions about how I'm going; support, you know and just all the conversation which is nice just to have a conversation with someone". (Participant #1)

Relationships between mental health consumers and health professionals are vital in the care of people living with severe mental illness (Ware, Tugenberg & Dickey 2004:555).

It is important for mental health consumers to establish a relationship with health professionals where they feel comfortable and see it as a good fit (Green, Polen, Janoff, Castleton, Wisdom, Vuckovic, Perrin, Paulson & Oken 2008:8). A caring and compassionate approach is a vital part of the establishment of this relationship (Green et al 2008:9). This has been referred to in the literature as a 'therapeutic relationship' (Cahill, Paley & Hardy 2013:783; Easter, Pollock, Pope, Wisdom & Smith 2016:342). Therapeutic relationships require mutual trust, respect and shared decision making. Respectful therapeutic relationships have been linked to improved outcomes for those living with severe mental illness (Farrelly & Lester 2014:449).

One participant expressed her gratitude to health professionals as she felt 'they saved my life'. This participant discussed how she had made plans to take her own life before mental health services were involved in her care:

"I actually left the hospital last week after having my final appointment with both the psychiatrist and the psychologist. They've actually discharged me back to a GP... I left there crying because they saved my life". (Participant #7)

These findings support the results of Ware et al (2004:556), who found that mental health consumers appreciated it when health professionals went out of their way to be helpful or did things that were "beyond the call of duty".

Although the majority of the participants described positive relationships with health professionals, some participants reported negative experiences.

One participant discussed how he felt ignored and unheard by health professionals. He felt that his opinions about his own treatment were not valued and was dismissed:

“That’s what I mean when I said like... the people at mental health are taught to say this is what’s wrong; this is how you get better – without actually listening to what I had to say”. (Participant #12)

Relationships with health professionals are undermined when mental health consumers feel misunderstood or not listened to (Green et al 2008:10).

Studies done by Ware et al (2004:557) and Green et al (2008:12), found that mental health consumers want to be involved in their treatment. According to these authors, this includes being consulted on matters pertaining to treatment, such as medication and making requests and having these honoured, and being listened to.

A participant continued to comment that he felt he did not receive help or support that assisted him in his journey of care:

“Well in my personal journey umm it was; there wasn’t much. The help that was there was no help, pretty much”. (Participant #12)

These sentiments were also echoed by another participant:

“And I stopped seeing her [referring to a psychiatrist] because I felt she didn’t support me properly. She supported me too late after I got put into [H Hospital] and I was angry with her about that”. (Participant #6)

When participants felt unsupported by health professionals, this was often related to not feeling heard or listened to and being dismissed (Ware et al 2004:557).

A participant described feeling disrespected by a health professional:

“There’s only been one staff member here who doesn’t treat me with respect”. (Participant #3)

Participant #3’s experience of not being treated with respect by a health professional is similar to the experience of some of the participants in Happell et al’s study (2004:245). The participants in Happell et al’s (2004:245) study felt disrespected by the doctors

working with them; as a result, they felt they did not receive the appropriate treatment and care. Disrespect for mental health consumers creates a barrier to the effective collaboration between mental health consumers and health professionals (Goodwin & Happell 2007:612). The results of the present study indicate that the relationships that the participants shared with mental health professionals form an important part of their social networks. Participants also described their relationships with friends as an important part of their journey with mental illness.

4.5.4 Relationship with friends

The participants described different levels of connections in their friendships. There were acquaintances, friends, and best friends/close friends. Friends formed an important part of participants' social support.

One participant described having two best friends and having the freedom to be himself in the relationships and being able to share openly with them:

"... Because they are my two best friends they know everything about me...it's something I've never hidden from them". (Participant #5)

Some participants discussed how they did not have many friends but the friends that they do have, were close.

"I don't really have many friends. I mean that's not true. You know all the time I was seeing the psychiatrist in [S city], I always had at least one friend. Close friend. They were males because I didn't trust women after my sisters". (Participant #6)

"I don't have too many friends but there's one of my best friends in [S city] we talk all the time and um she can tell if I'm sort of not well..." (Participant #11)

As part of social support, friends who knew the participants were able to identify signs and symptoms of mental illness in them. Friends were also able to determine the signs of relapse or the development of acute symptoms.

Other participants discussed more casual acquaintances they have contact with:

“Um my friend [Miss D] down at [the clubhouse], um... I got a friend [Miss HM] who’s been keeping in contact, I got a couple other people that I’ve talking to other than that. They’re just friends”. (Participant #8)

“I have a friend who lives on [M] Road, he comes every now and again, has a smoke out the back. A cigarette, rollie or whatever...” (Participant #9)

“... I have work friends yeah and a few neighbours that I get along well with. There’s an older bloke, [Mr K]; he lives in number two and he’s like, I get a lift up to the shops with him sometimes. Yeah, he’s pretty good. Good role model; good to talk to; have a chat with”. (Participant #4)

Participants explained that friendships were important to them. They liked doing activities with their friends such as going to the movies or going out for coffee or painting. For these participants, it was more than just completing the activities with their friends, but rather enjoying companionship, feeling understood and introducing some humour into their lives:

“I like my friend I go to the movies with. I like the friend I’ve got to go to coffee with. We have a lot of laughs; we understand each other well and we enjoy our time together”. (Participant #1)

“I was um, was going to a... painting group in Coledale a friend who was teaching me art... And um yeah- anyway that was nice. She’s a nice friend”. (Participant #9)

Rudnick, Kohn, Edwards, Podnar, Caird and Martin (2014:737) conducted a randomised controlled pilot study to investigate whether humour-based intervention would be effective to use with mental health consumers in practice. Rudnick et al (2014:737) found the results inconclusive but recognised that further study into this area was warranted.

Participants described that having conversations with their friends made them feel good and they could talk to their friends about anything:

“...Speaking with my friends makes me feel good”. (Participant #11)

“... My friend [Mr M] I can talk to him about anything. He’s a great friend. Been friends since I started to go to [the clubhouse]. That was back in 98”. (Participant #8)

Participants discussed how having a friend living with mental illness helped them relate better to each other due to having something in common and therefore having more understanding for each other. A friend living with mental illness was also more compassionate:

“Umm I think; think it was just because she was sort of like the closest person and she has her own mental health problems so we sort of related to each other”. (Participant #11)

“...He’s got his own... problems and all that sort of thing but he’s a good mate to have”. (Participant #12)

Davidson et al (2006:443) found that persons living with mental illness who have endured and overcome adversity could offer valuable support and encouragement to their peers living with mental illness. This is illustrated by the above participants who had friends living with mental illness and so were able to provide support to each other. Peer support has been found to reduce the use of emergency rooms and hospital admissions (Davidson, Bellamy, Guy & Miller 2012:123). It has also been established that peer support decrease a person living with mental illness’s symptoms of depression and psychosis, while increasing their sense of hope, belonging, ability to effect change in their lives, and satisfaction in their life domains (Davidson et al 2012:123; Pfeiffer, Heisler, Piette, Rogers & Valenstein 2011:29).

One of the participants discussed how he appreciated positive feedback from his friends as this encouraged him to be a better person. He liked being valued and appreciated and enjoying companionship:

“Some tell me um that they appreciate me and um some tell me that I’m doing good and look good you know and ahh yeah so verbally; yeah I get it verbally sometimes. Sometimes some friends don’t say it but that’s alright too. You know, I don’t expect to hear it from them but just to have a laugh or something with that type of friend is good enough, you know? ... and I know I’m healthy or know I’m, you know, doing something good because you know I’m enjoying my time with someone else and they’re enjoying their time with me”. (Participant #1)

This participant continued to discuss how he valued friends who understood and accepted him and did not stigmatise him or treat him as an outcast. Understanding in friendships was the most important thing for this participant:

“And a few understanding friends; they’ve played a major role in understanding mental illness and not putting that stigma on me or outcast on me and being unforgiving to me, you know, and saying, “There is something wrong with him; he’s never gonna be right.” or, “We won’t talk to him because there’s something wrong with him.” Yeah so they’ve taken that um blanket off the situation and understand. Understanding is the biggest thing yeah”. (Participant #1)

Despite numerous efforts to improve public understanding of mental illness, stigma remains one of the barriers impacting recovery for those living with mental illness (Wahl 2012:9). As a result of stigma, those living with mental illness may develop a poor self-esteem (Corrigan, Kosyluk & Rüsch 2013:794). Peer support has been found to moderate the adverse effects of stigma on self-esteem by encouraging those living with mental illness to disclose their mental illness diagnosis to others, such as work colleagues and friends (Corrigan et al 2013:797; Verhaeghe, Bracke & Bruynooghe 2008:206). Low levels of social support have been linked to higher levels of societal and internalised stigma and lower levels of recovery and quality of life. Social support, therefore, has been found to reduce the adverse effects of stigma on those living with severe mental illness (Chronister, Chou & Liao 2013:582-583).

Some participants discussed how they felt very supported by their friends as they felt they would always be available to assist:

"It's just when...you don't have to show it but I'm always there for them and they're always there for me. And the times I've had to um...ask for help from them...they were always there. No hesitation. Drop everything". (Participant #5)

"...I have some really good friends that, that yeah they're really supportive. Um.... I think...Yeah". (Participant #11)

"I've got a friend in [N city] who I'm sure would drop anything for me or the children". (Participant #7)

"They're a good support network. I can; they can see in me how I am um they're concerned about my health you know; they don't want me to um go off my medication or do things that will harm myself and they want me to be well and they want the best for me, which is really good, and I understand that these days". (Participant #1)

McCorkle, Dunn, Wan and Gagne (2009:299-300) evaluated the effectiveness of the Compeer Programme which is an intentional friendship programme that assists people living with mental illness form friendships. The participants in the programme echoed the same views regarding friendship as the participants in this study. Participants in the Compeer Programme discussed how they enjoyed doing various activities with their friend. They enjoyed support and a relationship of mutual reciprocity. They also appreciated acceptance and feedback with regards to their behaviour in the friendship. The findings of McCorkle et al (2009:299-300) are supported by the results of Mitchell and Pistrang (2011:158-159), who refer to the concept of 'befriending' rather than 'intentional friendship'. The participants in Mitchell and Pistrang's (2011:158-160) study appreciated empathy, understanding and support in their relationships. They also expressed how they enjoyed various activities with their friend.

One participant discussed how attending a support group had assisted her in learning to socialise with others. The support group thus formed part of her social network and in turn provided her with the social support she required:

"... When I was in [S city], I started to frequent a support group at a... local health centre... in the group I found that I was speaking to women about their lives...so

I was able to get to know them personally. They actually ended up becoming friends and they were part of my able to resocialise". (Participant #6)

The participants discussed how they were sometimes lonely as a result of having limited contact with others. As such, online friendships were more accessible for two of the participants who said:

"And on the computer a few friends on the computer that's about all". (Participant #10)

"... I've got a lot of online friends..." (Participant #5)

Vitak and Ellison (2012:8) and Forest and Wood (2012:297) found that users of online social network sites such as Facebook made use of these sites as a way of obtaining social support from other online users. Users of Facebook also appreciated the convenience of disseminating information without making an effort to use other means of communication, such as the telephone (Vitak & Ellison 2012:8). This was a convenient way for the participants who discussed having friends on the computer to access social support as these participants spent a considerable amount of time at home by themselves.

Some participants discussed how they had limited contact with friends:

"... I've got hardly any contact with anyone. So I still need; so I need to get a bit of confidence to go and do that..." (Participant #2)

"Not friend friends. Not that come and have coffee with me and- but that's how I like it". (Participant #7)

"I used to have a lot of friends..." (Participant #9)

Participant #2 wanted to gain confidence so that he could go out and meet people. Contrarily, Participant #7 advised that she preferred not having 'friend friends'. Participant #9 lamented the fact that she did not have as many friends as she had before being diagnosed with a severe mental illness.

These participants demonstrate how people living with severe mental illness face obstacles in acquiring and maintaining friendships (McCorkle et al 2009:292). The category of 'relationship with friends' is interlinked with the category 'contact with others' under the theme of 'Social Networks' which is discussed in more detail later in this chapter.

Living with mental illness was the second theme to emerge during data analysis and is discussed in detail below.

4.6 THEME 2: LIVING WITH MENTAL ILLNESS

The participants in the study were all living with a severe mental illness with the most common diagnoses among the participants being schizophrenia/schizoaffective disorder and bipolar affective disorder.

The participants described what it was like for them living with mental illness and the impact this had on their daily functioning.

One participant described how she was not coping with the housework or taking care of the children and her in-laws eventually raised the children:

"... I wasn't coping with the housework and the children ...and the children end up going to their inlaws". (Participant #9)

Another participant related how she was not coping well in society due to difficulties in her own family:

"... I wasn't coping very well in society. And um... and I think that that was really a consequence of the difficulties in my own family..." (Participant #6)

This was also experienced by another participant who felt that she was unable to cope or keep going as she was losing control of her life in general, including her children:

"I realised I couldn't keep going. I wasn't coping... I started losing control of everything. Lost control of the kids..." (Participant #7)

Another participant described how living with a mental illness affected her ability to complete her studies and to work:

“... I worked at the hospital doing a lot of voluntary work. So I’ve got a lot to fill in my resume and then I did a lot of TAFE courses. I did computing but I didn’t get through them because of my mental health problems; the stress of doing it. I did um computing, Certificate Four in Welfare, Vet Nursing, reception. I got through Animal Care completely um yeah. That’s just all in the 1990s so that was twenty years ago and then um my mental health got worse...” (Participant #3)

Other functional implications included not wanting to go out and be with friends, calling in sick for work, and not wanting to socialise with others. This is an example of social isolation from social networks which is illustrated by the following participant:

“...I just didn’t want to go out anymore and be with friends. I was calling in sick for work a lot. Just didn’t want to do anything. So, I was just just totally different”. (Participant #5)

Varcarolis (2013:13) describes mental health as the ability for one to successfully perform mental functions and so be engaged in productive activities, enjoy satisfying relationships, and be able to adapt to change and cope with adversity. Mental illnesses, on the other hand, are medical conditions that affect a person's mood, ability to think, ability to relate to others, and their daily functioning. Herzog (2013:505) further describes severe and persistent mental illness as those deeply affected by mental disorders. Severe mental illness has a significant effect on social functioning. Examples of disorders in this category include severe depression, schizophrenia, bipolar affective disorder, and panic disorders. Aside from difficulties with activities of daily living, other issues associated with severe mental illness include poverty, stigma, isolation, unemployment, and inadequate housing. Participant #5 described the isolation often experienced by those living with severe mental illness.

Other participants described how they were addicted to gambling, cigarettes and marijuana to try and cope with their ‘heartache’ (depression) and other symptoms of mental illness:

“I ended up gambling and that... I had a long affair with the poker machine over the years because of the heartache”. (Participant #8).

“...I have an addiction to cigarettes and there was a time when I had a pretty strong addiction to marijuana... I was using it as a pain reliever...” (Participant #9)

“...I was taking quite a fair few drugs in my time. Um pot was the main thing. Um ah I ended up getting hold of some dexamphetamine... probably ... a year after my symptoms started I was taking dexamphetamine pretty much every, at least 10 a weekend every weekend... do ten pills of dexamphetamine every weekend...” (Participant #12)

“...I'd been smoking pot... and uh I thought this house we were living in was haunted...” (Participant #10)

“I got referred from the [G team]... because um I had trouble with alcohol and drugs...” (Participant #1)

“... When I lost my dad I started using a lot of um hallucinogen drug drugs um ah like uh acid trips and things like that...” (Participant # 4)

Individuals living with mental illness have been found to use alcohol and drugs in order to ‘self-medicate’ against the disturbing and painful symptoms caused by mental illness (Harris & Edlund 2005:118). However, substance use has also been found to exacerbate the symptoms of mental illness (Harris & Edlund 2005:118).

One participant lost his job and his licence as a result of driving while intoxicated. He lost his licence for nine months, and this further exacerbated his symptoms of mental illness:

“... While I was driving home I got pulled over and lost my license for drink driving and um that was pretty much the beginning of my downfall sort of thing. Ahhh by the time... I lost my license. ... things were... ahh I was sort of stuck at

home. Um. Never got see anyone or do anything for about 9 months...”
(Participant #12)

Another participant also lost his job due to his mental illness:

“When I very first got unwell. I was at work and I just kept going to work and doing my things at work and after I think it took about six months and I my contract finished and I got the sack ...” (Participant #2)

Participants were also able to describe some of the circumstances that were occurring in their lives at the time they began to develop symptoms of mental illness. These included the death of a friend and increased anxiety levels at work:

“...My husband was a musician... and we were pretty busy and a friend... a close friend died and it sent me into a little bit of a... downward spiral... um... and I went into hospital on medication at the base... and I’ve been seeing mental health people ever since really. I’ve been on the pension since 1987...”
(Participant #9)

“I think when I was at work... um I found just my anxiety levels were getting out of control - and I’d just notice like some days like I would be ok with all of the other workers and I’d be out and talking to them and all that sort of stuff; and then I’d go through periods where I’d just almost sort of stay away from them. I’d just sort of stay in the office by myself. Um because I was pretty much the only one in the office. Then I’d just spend like days just sort of staying in there. But I think it was mainly more anxiety stuff that sort of made me go to the doctor”. (Participant #11)

A discussion of the symptoms of mental illness, medication, attitudes towards living with mental illness, hospital admission, and the influence to make use of mental health services, will follow below.

4.6.1 Symptoms of mental illness

The symptoms of mental illness influenced the function of the participants which in turn increased their need for support. The participants were able to describe some of the

symptoms of mental illness they had experienced to the researcher. These included feeling low:

"I was just really low. I wasn't suicidal just crying a lot". (Participant #3)

Being withdrawn and self-harming:

"...I was withdrawn... anti-social... um...and my regular interests were just not there". (Participant #5)

"Just very withdrawn from the world. I didn't want to be with anyone. I just wanted to sit in my room; have it dark, listen to my music, cut myself just didn't want to know..." (Participant #7)

They also experienced paranoia and delusions:

"I was really unwell and I was being really verbally um ah strange and sort of talking and stuff". (Participant #2)

"My thoughts were racing, I had a lot of paranoia; I saw a lot of strange things in my mind". (Participant #8)

One participant described how he had difficulty sleeping and had grandiose ideas that he was Superman:

"...I just wasn't sleeping and I was oh not really seeing things but I thought I was, like thought of grandiosi-a like I thought I was more than I was. Like thinking like I'm really Superman..." (Participant #4)

Participants also disclosed experiencing hallucinations, such as hearing voices:

"...Cause I was hearing voices and panic". (Participant #10)

"Um... and I still remember quite clearly like aboriginal dancing in a circle and all sorts of things... it was very frightening... you used to hear a lot of hear voices.

When I was driving around out here I'd hear a voice all the time. I was hearing voices... um... at that time... um... that went on for quite a few months". (Participant #8)

"It's all a bit of a blur after that. But then that was over a period of months. And that was the first psychosis that I had and then I went on to have other psychoses over the years" (Participant #10)

Denenny, Thompson, Pitts, Dixon and Schiffman (2015:164) found that among university students living with mental illness, those who recounted low levels of social support, reported higher levels of symptom distress, especially with regards to psychotic symptoms. Social support was found to be a moderating factor.

The symptoms of mental illness that the participants were experiencing resulted in a change to their normal behaviour, as illustrated by the following quote:

"... Just bits and pieces that my dad and step mother did say. They just noticed that I wasn't the same person". (Participant #5)

As a result of this family and friends around them could clearly identify these symptoms in them. This leads to the first person to notice symptoms.

4.6.1.1 First person to notice symptoms

As part of the symptoms of mental illness, the participants identified two main groups of people who first identified or noticed their symptoms of mental illness. These were firstly their family members (usually their parents), and then their General Practitioners (GP's): Not only were families the first to notice symptoms, but they were also responsible for connecting the participants with the initial assistance required:

"It was actually my family who noticed it and ah...they organised through a GP to see a psychiatrist..." (Participant #5)

"My family. My mother and father. They sought help from the mental health team". (Participant #1)

“Mum probably noticed when I was younger...my sister also and she brought me to hospital and that was when I was in [L hospital] for a few months”. (Participant #4)

Many people develop symptoms of mental illness within their family context and family members are often caregivers of mental health consumers (Bland & Foster 2012:518). Therefore, it is comprehensible why many family members were the first to notice symptoms of mental illness in mental health consumers. Family members are also responsible for putting mental health consumers in contact with mental health services, which is sometimes under coercion (Pescosolido, Gardner & Lubell 1998:275).

GP's were the second source that initially noticed or identified symptoms of mental illness in the participants. It was sometimes family members or friends who took the participants to the GP. At other times it was the participants themselves who presented to their GP's:

“ ...Not for a long time... not until my GP eh said I have schizophrenia”. (Participant #10)

“My GP after I first- I had been going to see him because of the problems in the marriage”. (Participant #8)

“...Oh you're going back a long time. So ah... it was a Dr down here in [C] Street... um... I can't remember her name... she was a woman...” (Participant #9)

Bambling et al (2007:126) and Steel, McDonald, Silove, Bauman, Sandford, Herron and Minas (2006:347) found that when it comes to people's first contact with mental health services, GP's play a pivotal role as illustrated by the above participants. GP's are often the first health professionals who are consulted for mental health problems. Thus, GP's are vital with regards to mental health consumers' use of mental health services. GP's were the first to notice symptoms and would, therefore, be the first health professionals to prescribe medication for symptoms of mental illness.

4.6.2 Medication

Participants identified that medication played an important part in their journey of living with mental illness. One participant mentioned:

“Well I had to get eventually the doctor prescribed me like a needle; like I’m on a depot and I had to go there every couple of weeks to get it. It was Risperdal that I was on back then”. (Participant #1)

Medication is a fundamental feature of mental health service utilisation as mental health consumers need to attend appointments regularly in order to obtain scripts for medication and have reviews with a variety of health professionals. The social networks formed by health professionals provide support that assists mental health consumers to remain adherent with their medication treatment regimes.

The participants had both positive and negative responses to medication.

The majority of the participants had positive attitudes towards medication and the medication they were taking:

“I’m on four different types of medication at the moment but um I don’t mind taking everything because it’s ... I can... it helps me recognize symptoms for what they are sort of thing. Yeah”. (Participant #12)

Another participant described how being put on medication had given her a sense of hope, otherwise, she would have given up:

“If they didn’t put me on the medications I’m on and provided me with what they provided me with... I would have given up”. (Participant #7)

Participants discussed the positive difference that medication had made in their lives. One participant disclosed that when she felt she was no longer coping, being put on medication made the difference in her life. Medication was part of seeking help for her:

“... I saw my doctor who put me on Pristiq which worked amazingly after 2 weeks. So I stayed on that um until last year 2014”. (Participant #7)

Another participant described how medication made a positive contribution to his life when he was unwell:

“Um where I felt hurt when I was unwell but medication sort of helped me understand and you know to let it go and not worry about it”. (Participant #1)

Another participant discussed how medication had assisted her to be mentally stable and she was pleased with the progress she had made:

Ahh the medication at the moment is um Flupenthixol...Epilim um and Effexor – the anti-depressant. I’m very stable at the moment”. (Participant #3)

Participants described how they had to try a number of different medications before they found a medication that worked for them, as illustrated by the following participant:

“I tried a fair few different medications before I actually found one that helped me”. (Participant #12)

Once participants found a medication that helped manage their symptoms, they were able to participate in community life and complete activities, such as studying. This is demonstrated by this participant:

“He increased my anti-depressant doses and he introduced another medication as well. A mood stabiliser which has really helped. And it’s been the mood stabiliser that’s gotten me to the point of... I’m ok. I can take on study”. (Participant #7)

Still another participant explained how being placed on medication had been the best thing that had happened to them as it had given them quality of life:

“... When I got put on Clopine that was the best thing that ever happened to me. It’s given me quality of life”. (Participant #10)

This was a sentiment echoed by a number of the participants. There seemed to be a correlation between being put on the right medication and quality of life that the participants were able to enjoy.

The experiences of the participants in the present study were similar to the experiences of the participants of Piat, Sabetti and Bloom's (2009:485) study among adults living with severe mental illness. Like the participants in the present study, the participants in Piat et al's (2009:485) study had mostly positive views on medication. They highlighted that medication was an important part of their recovery. Finding a medication that works was also vital to these participants as they believed that medication was responsible for keeping them mentally stable. The participants in Piat et al's (2009:486) study also cited the importance of taking the prescribed medication and adhering to it together with the social support available to them in the form of their families and friends and health professionals. Finally, these participants expressed the significance of having a say in their medication treatment regime (Piat et al's 2009:487). This was different from the participants in the present study who did not explicitly express during data collection that they would like to have a say in their medication treatment regime.

Those participants who had a negative response felt that medication was not helpful or effective in controlling their symptoms:

"Well that was the thing. I was actually put on a heap of different medication and as I was taking or when I was taking them it didn't help me at all..." (Participant #5)

"... My GP put me on a medication that really didn't help... it was Prothiaden and that didn't help the voices and all that. Um I'm not sure if it was the wrong medication". (Participant #8)

"Um I think. I think ...yeah, the first anti-depressant I was on didn't really work". (Participant #11)

"... I first got sick with depression when I was nineteen and I was put on anti-depressants but they didn't work". (Participant #3)

Velligan, Weiden, Sajatovic, Scott, Carpenter, Ross and Docherty (2009:1) identified that when medications were not effective in controlling symptoms of mental illness, mental health consumers were unlikely to adhere to their medication treatment regime. The participants in the present study did not report being non-adherent to their medication regime even at times when they felt their medication was ineffective.

Some of the participants shared how they had experienced life-threatening side effects as a result of the medication they were taking:

“My psychiatrist put me on Lithium which was a mood stabiliser and it caused me to have heart failure and kidney failure and I was dying of it...” (Participant #3)

“... And soon as they took me of clozapine, right off straight away cause someone had panicked cause me bloods were getting low and um... and I had massive seizures and I had an ambulance, 3 ambulances parked out the front.” (Participant #10)

Velligan et al (2009:1) and Lucca, Ramesh, Parthasarathi and Ram (2015:254) found that distress associated with specific side effects of medication and general fear of side effects, significantly contributed to mental health consumers not wanting to take prescribed medication.

Another participant continued to state how being changed over to another medication saved her life:

“... So it was changed over to Epilim and um so I’ve still got kidney problems. It saved my life changing over to Epilim because I’ve got epilepsy as well”. (Participant #3)

Only two participants disclosed that they did not like taking medication, but they continued to take it as demonstrated by the following quote from one of the participants:

“I don’t particularly like being on medication...and I’ve been ah... taking it like I’ve been told to”. (Participant #9)

Velligan et al (2009:1) and Adams and Scott (2000:119) found that mental health consumers, like the above participant, who did not like being on medication had limited insight into their mental illness and this influenced their attitude towards medication and their attitude towards living with mental illness.

4.6.3 Attitudes towards living with mental illness

The study findings identified a number of attitudes towards living with mental illness. Firstly there is the family's attitude towards mental illness, the consumer's attitude towards mental illness, and society's attitude towards mental illness.

Some participants reported that it was difficult for anyone to convince them to get help when they were unwell because at that time they do not believe they are unwell:

“Um... it's very hard for anyone to convince me to get help when I'm not well cause when you're that unwell you don't think you're unwell”. (Participant #8)

Participants also identified that when they were unwell it was difficult for them to understand what was happening:

“I just wasn't ready and I was- everything was very chaotic and ah um I just didn't quite understand what was happening to me”. (Participant #6)

Some participants identified the role that their family members played:

“Well my sister prompted me to talk to her; to go and see her and um I just thought she was full of rubbish to be honest because she was describing all these things which sort of what I had but weren't what I had. I thought it was just a waste of time what she was talking about; you know, there was nothing wrong with me; I was alright. I thought there was more something wrong with her, you know?” (Participant #1)

Relatives of those living with severe mental illness face multiple concerns. These include feeling love and compassion towards their family member living with a mental illness, and a sense of duty or responsibility towards them. This makes it difficult for

relatives to establish balance in their own lives. Relatives also need care and support as part of the holistic care and support of the person living with mental illness (Weimand, Hall-Lord, Sällström & Hedelin 2013:99).

The family's attitude towards mental illness is discussed below.

4.6.3.1 Family's attitude towards mental illness

Some of the family members of the participants were supportive (7 out of 12) while others (5 out of 12) were not supportive of the participants. The family members who were supportive, demonstrated understanding:

"Most of my family are quite understanding". (Participant #1)

Family members also demonstrated support and care:

"Oh it affected them when they found out that I was ill and when I had the relapses and the bad times. They'd get scared and get worried but um they've been really supportive too. In the bad times, visiting me in hospital and things like that". (Participant #4)

Many family members are now responsible for the care and support of their family member living with mental illness in the community (Bland & Foster 2012:518).

This participant continued to explain that although his family was supportive, there were those family members who were not supportive because they lacked understanding:

"Some of them are a bit stand-offish still because they don't quite understand". (Participant #1)

One participant was resentful due to his father not understanding his mental illness:

"My dad's general attitude was there's nothing wrong with you; get a full time job and stop your whinging sort of thing. That's always been him no matter what, really". (Participant #12)

Family members who do not understand mental illness may become angry or resentful towards those living with mental illness (Nicholson, Sweeney & Geller 1998:646).

When family members ignore or fail to acknowledge the mental illness of mental health consumers, they may feel rejected and ostracised by them (Robinson, Springer, Bischoff, Geske, Backer, Olson, Jarzynka & Swinton 2012:312).

Family members who look after their relative living with a mental illness often have to deal with the emotional stress of looking after their relative, the symptoms associated with mental illness, and the emotional and physical stress as a result of the attitudes or actions of their relative living with mental illness. Family members also have to deal with the societal stigma of having a relative living with mental illness (Pusey-Murray & Miller 2013:118; Saunders 2003:175). The burden of care is significantly increased if the relative living with mental illness lives with family members. (Östman 2007:35). Only two of the twelve participants in the present study lived with their relatives. The remaining ten participants lived alone.

Another participant described how her husband labelled her 'crazy' because of her mental illness:

"Well my husband said I was crazy all along but (laughs) he was pretty crazy himself". (Participant #8)*

*Field note indicates that the participant laughed when she expressed this comment and slapped her hand against her thigh.

In their study, Nicholson et al (1998:646) found that partners or ex-partners of women living with mental illness would often tell them to "snap out of it" or "get over it". However, psychoeducational programmes that are designed for educating family members have been found to be effective in changing family members' negative attitudes towards severe mental illness, such as schizophrenia (Gutiérrez-Maldonado, Caqueo-Úrizar & Ferrer-García 2009:343). Family members are also able to influence mental health consumers' attitudes towards mental illness (Redlich, Hadas-Lidor, Weiss & Amirav 2010:09).

4.6.3.2 Mental Health Consumers' attitude towards mental illness

Most of the participants disclosed that they believed they were normal and did not consider they were unwell when their symptoms were acute. This denial was correlated with lack of insight during acute stages of their illness:

“I just thought I was normal. I was doing something normal you know ‘cos that’s what my brain was telling me. I was doing normal; to do these things, there’s nothing wrong with me”. (Participant #1)

“And also I didn’t believe that I was ill... at the time.” (Participant #8)

Cramer (2012:36) describes denial as a defence mechanism where a cognitive strategy is employed where attention is withdrawn from external stimuli that would cause psychological pain or upset if they were acknowledged or recognised. In the present study, the participants’ denial was correlated with their inability to recognise the severity of their mental health symptoms during the acute stages of their illness.

Mental health consumers who live with a severe mental illness such as schizophrenia may demonstrate poor insight into their mental illness, and this has an impact on their overall functioning and treatment adherence, especially when their symptoms are acute (Lincoln, Lüllmann & Rief 2007:1324). However, some authors have also found that when the level of insight improves for those living with a severe mental illness such as schizophrenia and schizoaffective disorder, this negatively impacts their quality of life as it serves to decrease their level of hope (Hasson-Ohayon, Kravetz, Meir & Rozencwaig 2009:231).

One participant compared living with schizophrenia to the physical pain he had experienced in his life. He described living with schizophrenia as being worse than any physical pain one could experience:

“I’ve had a lot of physical pain in my life and a fair bit of physical sickness. But schizophrenia is HELL. Alright? It’s worse than any physical pain. I think it’s the most serious illness there is. Maybe bi-polar but I’ve never been bi-polar so I wouldn’t know...” (Participant #10)

Participants also discussed how they stigmatised themselves:

“I always shunned that; took a bit of a stigma and all that stuff and said I wasn’t ill enough to have all that; I didn’t need that and could do it on my own and I didn’t want the stigma being on me if someone saw me going in to mental health all the time”. (Participant #1)

Stigma refers to the prejudice and discrimination experienced by those living with mental illness (Corrigan & Rao 2012:464). Mental health consumers have highlighted the stigma associated with mental illness in rural communities. This negatively impacts on mental health consumers’ help-seeking behaviour because in a small town ‘everybody knows everybody’s business’. Mental health consumers are therefore reluctant to disclose that they have a mental illness because of the fear of stigma and labelling which can negatively impact their lives. This can cause mental health consumers to internalise this stigma (Robinson et al 2012:311-312).

Self-stigma occurs when a mental health consumer internalises societal messages about mental illness and experience numerous negative consequences as a result. These include poor self-esteem, depression, and loss of self-efficacy (Corrigan & Rao 2012:464; Luckstad, Drapalski, Calmes, Forbes, DeForge & Boyd 2011:51). High levels of self-stigma and insight among individuals living with severe mental illness have been correlated with a poorer quality of life and feeling that life has no meaning (Ehrlich-Ben Ora, Hasson-Ohayona, Feingolda, Vahaba, Amiazb, Weiserb & Lysakerc 2013:198). In the present study, only Participant #1 explicitly referred to self-stigma.

Societal views have an enormous influence on how mental health consumers see themselves. Society’s attitudes towards mental illness are discussed below.

4.6.3.3 Society’s attitude towards mental illness

The participants described the stigma that they experienced from the wider community as part of being employed or engaging in community activities, as a result of their mental illness. Participants also discussed public perceptions of mental illness and those living with mental illness.

A number of participants highlighted the stigma they experienced that is attached to mental illness:

“There’s not enough acknowledgement out there and there’s not enough information for mental health and there’s such an awful stigma attached to mental health”. (Participant #7)

The rural mental health consumers who participated in Robinson et al’s (2012:316) study identified that there was stigma in the general community as a result of ignorance. They proposed that providing education and information to community members would help to reduce the stigma around mental illness.

Participants discussed how they were branded as crazy in the eyes of the public:

“It’s sorta ahh you get branded as crazy... I know it sounds silly... but the general; general public... in that you get branded just pretty much as crazy”. (Participant #12)

Stigma is mainly based on stereotypes. Public perceptions of those living with mental illness include seeing them as dangerous, crazy, or people who cannot be trusted (Link, Phelan, Bresnahan, Stueve & Pescolido 1999:1328).

Recent studies have found that most of the attitudes of the general public towards those living with mental illness were negative. Most of the participants reported public perceptions that those living with mental illness were less intelligent, abnormal and less trustworthy. Participants also believed that those living with mental illness would be denied opportunities for employment, education, friendships and intimate relationships (Liu, Yan, Ma, Guo, Tang, Rakofsky, Wu, Li, Zhu, Guo, Yang, Li, Cao, Li, Li, Wang & Xu 2016:443; Razali & Ismail 2014:176).

One participant described how she had experienced discrimination within her workplace as a result of her mental illness. This participant was forced to resign from her job as a consequence:

“My two bosses came back and they said it was time for your medical so I had to go before the medical officer and ahh I was honest. I said, “I’ve got depression. They said either you resign or we give you the sack and if you don’t resign you’ll never get a job in the Commonwealth government again”. (Participant #3)

Cechnicki, Angermeyer and Bielańska (2010:643) in their study of adults living with schizophrenia, found that their participants both anticipated and experienced stigma. Like the participant above, some participants experienced discrimination within their workplace as a result of living with a mental illness. Having said that, the majority of their participants anticipated stigma and discrimination in their interpersonal contacts.

Previous research has found that people living with a mental illness in countries with less stigmatising attitudes experienced higher rates of help-seeking and mental health service utilisation when compared to countries with more stigmatising attitudes (Evans-Lacko, Brohan, Mojtabai, & Thornicroft 2012:1741).

A number of the participants had required hospitalisation at some point during their lives due to their mental illness. These experiences are discussed below.

4.6.4 Hospital admission to a mental health facility

Hospital admissions to mental health in-patient facilities formed a large part of the participants’ journey of living with mental illness. Participants were usually admitted to hospital during an acute phase of their mental illness:

“...They took me to the hospital and um then at the base hospital at [DV town] and then [LT town] and the doctors saw me there and then they drove me to [B city] to a psychiatric hospital”. (Participant #2)

Medication non-adherence has been linked to decompensation of mental state and hospital admissions (Swartz, Swanson, Hiday, Borum, Wagner & Burns 1998:226).

Often after a hospital admission a participant was able to return to baseline functioning as demonstrated by the following participant:

“I had an admission in the mental health unit in [BB] in about 90...7, I don’t really recall what treatment or anything I had. I think got back on track fairly quickly and I wasn’t on any medication”. (Participant #5)

Hospitalisation to a mental health unit can address a number of functional deficits to improve the daily functioning of those living with mental illness upon discharge so that they are able to live independently in the community (Lipskaya-Velikovsky, Kotler, Easterbrook & Jarus 2015:499).

Participants reported a number of hospital admissions to different hospitals. This was often related to how long a participant had been living with their mental illness.

“Well I had quite a few admissions to hospital... I’ve had admissions to [JF] clinic in [N city] also um...[B hospital]... maybe half a dozen admissions to [B hospital] in [T town]”. (Participant #9)

“I’ve had well over 20 trips to [B hospital]... more close to 25, 30 now over a period of time. And um Dr [BW] when I had some health insurance... she sent me to [NS] clinic for 5 weeks”. (Participant #8)

Mental health consumers who have frequent hospital admissions or re-admissions are sometimes referred to as ‘revolving door service users’. Factors associated with being a ‘revolving door service user’ include: being on medication, being younger at the age of the first contact with mental health services, living in government housing, and having a more enduring and chronic mental illness (Webb, Yáguez & Langdon 2007:647).

The participants in this study enjoyed varying levels of social support. Since the inclusion criteria for participation in the study was that a participant had to be diagnosed with a severe mental illness, all the participants were involved with a mental health team case manager to a greater or lesser degree. It was a participant’s family members or case manager who would often facilitate a hospital admission. The factors that influenced the participants’ use of mental health services, are discussed next.

4.6.5 Influence to use mental health services

With regards to influence to use mental health services or seeking help, the participants had varied responses. They described a professional influence and a personal influence which included both themselves, friends and family. The professional influence included the follow-up of the participants, monitoring mental state and ensuring the participants attended scheduled appointments. Health professionals were also responsible for monitoring medication adherence and making sure they were available and accessible to the participants. Personal influence was often demonstrated by friends or family members encouraging the participants to contact mental health services in order to seek assistance for their symptoms of mental illness.

A number of participants (4 out of 12) discussed the professional influence to use mental health services. This often came in the form of the mental health case managers:

“Well [Miss L] does, my personal counsellor. She um, she makes appointments for me with my psychiatrist to get medication”. (Participant #9)

“Well the mental health services themselves influence my decision... because they keep in contact and um... they make the appointments with the psychiatrists and I always stick to my appointments and so really it’s coming from the other way round really. (Participant #8)

“...I was in hospital and then it was then when I was getting out and um ahh it’s – [Mr CB- case manager] was there and helped me through a pretty rough patch...” (Participant #12)

One participant expressed how the mental health team was important to them because they could always turn to them if they needed help.

“I’d say the mental health team is important to me because um there’s someone I can go to if I do have trouble. You know if something does go wrong well then I don’t know what to do I can go to the mental health team umm and they’re pretty good.... umm and my friends”. (Participant #1)

Some participants reported that no-one influences their decision to use mental health services. Thus, they discussed their personal influence of deciding to use mental health services:

“To use mental health services... No it was always a decision I made on my own”. (Participant #6)

“To use the mental health services? Well I made the decision to use the mental health services...” (Participant #3)

“Me. I made the choice. As I grew older um I decided that I needed help and it was really me that made the decision to get it”. (Participant #4)

“No I just make the decision myself to do it”. (Participant #2)

The participants also discussed the personal influence of friends and family that influenced their decision to use mental health services:

“I think my friend [Miss S], she sort of ... I think the first time I went into hospital it was [Miss S] that sort of rang the ambulance.... but she was the first one that sort of... we talked about needing to go to the doctor and things like that”. (Participant #11)

“Well, my mother of course. She was the one who went and talked to the doctors about it”. (Participant #10)

Villatoro and Aneshensel (2014:174) suggest that the influence of family on mental health service utilisation may not persist once a need for care has been established. They suggest that families indirectly affect mental health services utilisation by affecting need.

Social networks and social support have been found to influence mental health consumers' use of mental health services (Albert et al 1998:248). Social networks result in social influence which affects health promoting behaviours (Kawachi & Berkman 2001:460). The decision to seek help for one's mental illness may be facilitated by

having a relationship with someone who recommends that you seek help or has sought help themselves (Vogel et al 2007:233).

One participant described how in their journey of seeking help for their mental illness, they were not able to get the right help. However, now they were able to get the help they need:

“Umm ‘cos I seek the help. I’ve always been able to ahh lately I’ve been able to get the help. In the past I haven’t been able to get the help”. (Participant #3)

Other participants discussed how as a result of not coping in their lives, they reached out for help:

“I think... I did...I did for a certain period. Um... because I wasn’t coping with the external events that were happening in my life. I just wasn’t coping with it and I needed the support um... I had to reach out...” (Participant #5)

Women have more positive attitudes towards seeking help and are more open to seeking help from mental health professionals when compared to men (Mackenzie, Gekoski & Knox 2006:574). This is confirmed by the participants in this study as the female participants were the ones who reported more positive experiences in their help-seeking journey.

Another participant commented that if they had not received help at their point of desperation, they would not be alive today. They also needed the help in order to feel contained:

“And I went to the doctor here. It was Dr [R] and was just completely honest with him and begged him for help. Because if I wasn’t honest with him again I would be here talking to you. I’d be 6 foot underground. Cause that is the only way I could get peace and normality”. (Participant #7)

The participants in the study were more open to seeking help for their mental illness. However, this is not often the case with adults in the general population. Many people are reluctant to seek help for mental health symptoms for a number reasons. These

include negative attitudes towards seeking help generally, concerns about cost, transportation, confidentiality, or feeling like they can handle the problem on their own (Gulliver, Griffiths & Christensen 2010:2; Robinson et al 2012:313-316). Rüsçh, Müller, Ajdacic-Gross, Rodgers, Corrigan and Rössler (2014:185) found that participants in their study, who were adults in the general population, had negative views in terms of seeking professional help and using mental health services for themselves and also with regards to making recommendations to others. Participants were also found to have negative views towards psychiatric medication. In the present study, only two participants expressed negative attitudes towards medication. The majority of the participants had positive views about medication.

An important part of mental health is physical health. The physical health of the participants, along with its effect on their mental health symptoms, is discussed below.

4.6.6 Physical health impacting on mental well-being

A few of the participants explained how their physical health impacted on their mental well-being. One participant who was living with knee pain described how living with this pain had contributed to mental health admissions to hospital:

“I think as I’m getting older... I’ve got a bad left knee... that’s been a lot of the problem previously. Even though I’ve had a couple of admissions which I don’t say has been because of the pain, the pain has been what has not triggered it but part of what’s brought me down”. (Participant #5)

Another participant disclosed how an upcoming hip operation had served to increase her anxiety levels.

“I’m having this hip operation... and I’m very nervous about it. Cause ah, they’ll be cutting open my eh, my hip”. (Participant #9)

One participant explained how his physical concerns were not addressed when he went to see his new GP:

“...I had a doctor in between Dr [M] and this one, but um he really didn’t care at all. He was no support. He’d ... he wouldn’t take the time. I’d say I’ve got spots all over me that I need to get checked and he wouldn’t do it pretty much, so ...”
(Participant # 12)

Jones, Howard and Thornicroft (2008:170) discuss the concept of ‘diagnostic overshadowing’ in mental illness where a doctor may attribute a person’s physical health complaints to their mental health symptoms. The above participant felt that his GP did not take his physical concerns seriously as a result of his diagnosis of a severe mental illness, and he did not feel that he received the appropriate care from his GP. This correlated with the stigma that mental health consumers experience as a result of their mental illness.

One of the participants explained how they used deep breathing in order to control their symptoms of anxiety and stress.

“...What do I do when I get uptight? Concentrate on me breathing in me lower abdomen... lowers your centre of gravity and causes you to relax...” (Participant #10)

People living with severe mental illness have more physical conditions prevalent when compared to the general population. This leads to a shorter lifespan when compared to the general population. This shortened lifespan is a result of physical illnesses, side effects of medication, poor access to health services, and individual lifestyle choices (DeHert, Correll, Bobes, Cetkovich-Bakmas, Cohen, Asai, Detraux, Gautam, Möller, Ndeti, Newcomer, Uwakwe & Leucht 2011:52; DeHert, Cohen, Bobes, Cetkovich-Bakmas, Leucht, Ndeti, Newcomer, Uwakwe, Asai, Möller, Gautam, Detraux, & Correll 2011:138; Thornicroft 2011:441).

The third theme to emerge during data analysis was social support, and this is discussed below in detail.

4.7 THEME 3: SOCIAL SUPPORT

In general, participants viewed social support as the physical and emotional presence of a person in their lives. Participants saw social support as a person knowing their true selves and someone seeing them at their best and at their worst.

One participant defined social support as knowing you will be supported:

“Mmh... you just know these things... you know... you know they keep contact with me it’s not just me contacting them”. (Participant #8)

Another participant, when talking about his mother, defined social support as his mother staying with him and supporting him in spite of challenges:

“She’s been with me through hell all- most of me life. She stuck by me, that’s how I can tell...” (Participant #10)

Still another participant defined social support as his mother being there for him:

“Yeah she’s been there. We haven’t always gotten along but ... um it worked pretty much like that. It’s just me and mum so”. (Participant #12)

The majority of the participants felt that there were people they could turn to if they needed help:

“There would be a few people that I could lean on if I really had to”. (Participant #7)

“I think like my Dad and Step-mum if I did go into hospital um after I got out they would take me and I’d spend a week or so with them to try to sort of get used-or settle back down”. (Participant #11)

“Well, they sort of know my story so they’ve seen me at my best and my worst and I feel like they’d be there for me....” (Participant #1)

Chronister, Chou, Kwan, Lawton and Silver (2015:236) explored the meanings those with severe mental illness ascribe to social support and found that those living with severe mental illness wanted those who provide social support to them to know that their mental illness sometimes influence their ability to execute daily life tasks, such as leaving the house, going to work, and being with other people. Individuals who treated them with an attitude of acceptance, affection, respect and value were perceived as supportive (Chronister et al 2015:236).

Kamenov, Cabello, Caballero, Cieza, Sabariego, Raggi, Anczewska, Pitkänen and Ayuso-Mateos (2016:7) investigated the reasons why those living with a severe mental illness have poor social support and found that lower levels of disability were associated with higher levels of social support. In other words, the more severe a person's mental illness is, the less social support they receive. The findings of the present study reflected that the more severe a person's disability was, the more support they received from community managed organisations (CMO's) and mental health services in the form of case management.

The participants categorised social support into four different types, namely; emotional support, physical support, financial support, and the support they received from mental health services. These are discussed in detail below.

4.7.1 Emotional support

Participants described emotional support as talking to friends and family who are concerned about their well-being.

One participant expressed how she relied on her friends for emotional support:

"I think because ... my friend [Miss MM] she's sort of happy.... we sort of discuss things that she like doesn't talk about to other people and that I don't really talk about to other people". (Participant #11)

Other participants relied on their families for emotional support:

“I have my family in [N Country] too... if I really was in big trouble um I could talk to them”. (Participant #8)

“They’re a good support network [family]. I can; they can see in me how I am um they’re concerned about my health you know...” (Participant #1)

“Ahh well at the moment it’s just me and Mum really. Ahh [Health Professional C-case manager] I know [Health Professional C] is there if I need to make an appointment I can talk to him but other than that I’ve got a couple of good friends in town”. (Participant #12)

Participant #12 also discussed how his case manager [*Health Professional C*] was an important part of his emotional support as he was available for the participant to talk to and the participant felt that [*Health Professional C*] was concerned about his emotional well-being.

The following participant highlighted the importance of emotional support as she discussed how it made her feel good. She did, however, add that with her parents this was sometimes not the case:

“Um I think.... Yeah I think speaking with my friends makes me feel good. Um... Sometimes... I think... yeah sometimes my dad and step-mum make me feel good but other times I ... like that’s sort of not as much (chuckles)”. (Participant #11)*

*The field notes reflect that the participant was laughing (chuckling) when she shared this comment.

Another participant described how the emotional support received from his family was critical, especially when he was in hospital. The participant’s family were able to provide advocacy for him and take over some of his responsibilities where he lacked capacity:

“Um well they supported me when I was in hospital. They um not just through communications to say look I think you’re on the best thing but they were sort of my guardians too umm”. (Participant #1)

Emotional support occurs when one is able to spend time with another person listening and talking about things that concern them or problems they may have (Adams, King & King 1996:412; Slevin, Nichols, Downer, Wilson, Lister, Arnott, Maher, Souhami, Tobias, Goldstone & Cody 1996:1275).

Hogg and Warne (2010:297) found that lay-people, such as beauticians, priests, hairdressers and bar-girls, formed an important and yet informal part of the emotional support for those living with mental illness in the community. These authors found that those living with mental illness in the community would disclose to beauticians, priests, hairdressers and bar-girls about their problems as they found them non-judgemental and easy to talk to. These lay professionals would, in turn, point their clients in the right direction as to where they can obtain the help they need (Hogg & Warne 2010:300).

Low levels of social and emotional support have been associated with an increase in mental distress, anxiety, depression, poor sleep and pain (Strine, Chapman, Balluz & Mokdad 2008:151). Having a high level of emotional support has in turn been associated with decreased symptoms of mental illness (Smyth, Siriwardhana, Hotop & Hatch 2015:1118). This view has also been supported by Tempier, Balbuena, Lepnurm and Craig (2013:1897), who found that higher levels of perceived emotional support were associated with longer periods of remission after an initial episode of psychosis. An important part of social and emotional support is physical support, which is discussed in detail below.

4.7.2 Physical support

Participants defined physical support as the practical help that was offered to them by family or friends. This included cooking meals, facilitating hospital admission, looking after their property while in hospital, and mowing the lawn. The following participant described how his mother prepared meals for him to ensure that he had food to eat:

“Mum cooks meals and all that sort of thing and uh keeps me pretty well fed”.
(Participant #12)

One participant explained how the physical support provided by his family was instrumental in facilitating hospital admission when he was unwell:

“Um in getting me into hospital type of thing like next-of-kin um...” (Participant #1)

Physical support was also critical to this participant during his hospital stay and knowing that his family would look after his flat while he was in hospital:

“...Bringing clothes up and that type of stuff and looking after my jobs at home like doing the mail or you know um checking on the flat”. (Participant #1)

Many family members wanted to make life easier for the participants and so provided physical support:

“I had my daughter come down. I had a lot of stuff on the verandah, so my daughter came down and cleared it all out... and um... we took it to the op shops and stuff like that because my daughter... wanted, wanted to make things easier for me.” (Participant #9)

A friend assisted the above participant by mowing her lawn:

“I’ve got- a friend came and mowed my lawn the other day”. (Participant #9)

Physical support is also described in literature as instrumental support. This is the practical and tangible support that is aimed at solving a problem (Adams et al 1996:412; Thoits 2011b:147). Physical (instrumental) support has been found to be essential for the day-to-day functioning of those living with severe mental illness. This includes supports with practical tasks, such as grocery shopping, and also assistance getting to appointments (Chronister et al 2015:237).

Perceived emotional support and physical (instrumental) support have been found to be protective factors for mental health disorders (Smyth et al 2015:1111). In contrast, Levens, Elrahal and Sagui (2016:352), in their study among university students with depression, found that physical (instrumental) support provided by families did not have an effect on depressive symptoms. Financial support is an important part of physical support and this will be discussed next.

4.7.3 Financial support

In general, participants defined financial support as family or friends giving them money or lending them money to purchase items such as cigarettes:

“Oh they might; my family and that they do give me financial assistance. A bit of money. Ahh that’s probably about it”. (Participant #2)

Another participant elaborated on this by saying that financial support was not just about money, but about family or friends buying them items when they were in need:

“Oh well Mum will lend me some money if I need it, but it doesn’t have to be money. Um. Or my mate will buy me a packet of ciggies if I’m short one fortnight. Or um just generally looking out for me”. (Participant #12)

This participant discussed how he was trying to live life on his own and so did not want to ask for money from his family members, although in the past they had provided for him financially:

“Mum’s very like when I was struggling when I wasn’t working; she supported me with money. Financially and my brother is supportive like that as well. If I need something I can always ask him ‘cos he’s in a bit better situation than I am. Like, not physically but financially he’s a lot better off, but I try not to ask him for money. ‘Cos I don’t want to borrow money off my family anymore. You know, trying to do it on my own, sort of ... yeah”. (Participant #4)

Financial support is a part of the physical or instrumental support provided by family and friends as it involves offering material assistance (Thoits 2011b:147).

The majority of the participants (8 out of 12) received their income through the disability pension every fortnight. This is illustrated by the following participant:

“...I’ve been on the pension since 1987...” (Participant #9)

One participant supplemented the income they received from the disability pension through part-time work:

“Yeah part-time. Mondays and Fridays, 2 hours a day at the moment”.

The financial support provided by the disability pension is an important part of financial support, although this was not explicitly expressed by the majority of the participants.

Financial support for those living with mental illness is imperative as they have been found to be among society's most poor, which further exacerbates their symptoms of mental illness (Anakwenze & Zuberi 2013:147; Wilton 2004:26). Mental health services provide critical support for mental health consumers. Their role and the support they provide is discussed below.

4.7.4 Support from mental health services

The majority of responses from participants with regards to the support they received from mental health services were positive. The participants identified that the support they received from mental health services provided safety for them, assisted them with practical tasks, monitored their mental well-being and activities of daily living, including being employed. The most positive response was from the following participant who stated:

“I can't fault the mental health system through the hospital. They've been absolutely wonderful”. (Participant #7)

Another participant echoed the above sentiments:

*“I would have been stuffed without the mental health services though...”
(Participant #8)*

This participant commented that mental health services had provided her with a safe haven:

“I think that provided me with a safe haven...” (Participant #6)

The following participant was pleased with the support that she had received from her previous GP and case manager. She was appreciative of the support she had received from mental health services:

“...My last GP she was really like she said that I could go to her whenever; I could ring her whenever I wanted to and she’d ring me back and um I felt sort of really supported by her.... um and [Health Professional M - case manager] been really great. She um has been really supportive and I find her really helpful”.
(Participant #11)

Mental health consumers have identified that they appreciated it when mental health professionals within mental health services treated them with respect and compassion and showed a genuine interest in their personal well-being. Mental health consumers also highlighted that they valued clear communication regarding the process of care (Gunasekara, Pentland, Rodgers & Patterson 2014:106).

Mental health services were also able to offer participants the following types of support: monitoring medication and mental state, and education regarding living with a mental illness:

“With my state of mind and the way I’m feeling now the doctors are just monitoring my state of mind and my medications which I’m hoping will be decreased the next time I see them”. (Participant #5)

“... They’ve sort of encouraged me to talk... and ah encouraged me with my medication and encouraged me with my life that I lead; my understanding of schizophrenia that I was born with it. I, like, you know, it wasn’t just something that happened to me; it’s a disease and an illness. They’ve explained it; people have explained it; in the health services to me”. (Participant #1)

The participants in Chronister et al’s study (2015:237), shared the same views at the participants in the present study. They appreciated the support they received from mental health case managers, such as medication monitoring and regular checking in and monitoring their mental state. The participants, like the participants in the present

study, also appreciated the practical support offered by mental health case managers (Chronister et al 2015:237).

Some case managers assisted the participants with practical tasks such as shopping, as illustrated by the participant below:

“I have a counsellor called [Health Professional L]... she’s very good...very nice... she takes me shopping and helps cause I had a couple of car accidents in my car. I haven’t been... confident enough to drive”. (Participant #9)

Mental health services were there to provide reassurance if the participants needed to visit the mental health section of the emergency department, as expressed by the following participant:

“...One time I had to go up to emergency...and [Health Professional D] was there... and he knows me... and he was great. I was having a really severe full on attack and I knew I had to go to emergency. And [Health Professional D] was really good and he was really reassuring”. (Participant #10)

The following participant conveyed how the support and life skills training they received from mental health services has helped them keep their job and move in a more positive direction in their life:

“Well it’s been good because it’s helped me to hold down a job and just function better in society so... Otherwise it’s helped me move into a better direction um of managing my medication and also life skills and living a healthier life without the drugs and um yeah, with, with the support”. (Participant #4)

The following participant was the only participant who initially had a negative experience with regards to the support received from mental health services. He was then able to have a positive experience years later, after he met his case manager [Health Professional B]:

“Ah umm pretty much just said that there really wasn’t any help for me to begin with. Umm It wasn’t until really that I met [Health Professional B] here at [Facility

D] all these years after that I actually started ... the help he gave me was umm it was really valuable and um I hadn't got that anywhere else". (Participant #12)

Participant #12's initial negative experience is similar to the experience of respondents living with severe mental illness in Wang, Demler and Kessler's (2002:92) study. The majority of respondents in that study reported that the care and treatment they received was not sufficient to meet their needs.

The same participant continued to describe how his case manager was an important liaison in order to facilitate his employment:

"Yeah yeah having a good liaison through [Health Professional B] with the system. Coz once I was feeling more on track and my medication was stable umm it was [Health Professional B] who put me on to [the employment agency] and they are the ones who have helped me keep a job for the last 3 years..." (Participant #12)

One participant wanted mental health services to be more readily available after business hours for additional support:

"When ah... I first got ill... you know like weekends and that and you if you weren't well and you rang the line they would turn up on the weekends and that as well... it was very helpful. But now it's just 9 to 5". (Participant #8)

Tsai, Desai and Rosenheck (2012:144) in their study involving adults living with severe mental illness, found that those with severe mental illness did not rely more on professional support and less on informal social support, such as family and friends. Instead, the informal social support provided by family and friends was found to complement professional support rather than substitute it. Tsai et al's (2012:144) findings support the results of this present study, as this was the experience of the present study's participants.

The research findings support the notion that an increase in social support increases the use of mental health services by mental health consumers. Social support and social networks go hand in hand, and a discussion of social networks follows next.

4.8 THEME 4: SOCIAL NETWORKS

The final theme to emerge during data analysis was social networks. The participants identified that social networks were the people that they had frequent contact with. These included friends, family, colleagues, and mental health professionals. Social networks also included support groups, community groups, hobby groups, church, and the people who operate the tills at supermarkets. The participants' social networks provided them with routine, social interaction and a sense of purpose. Social networks were further divided into the two categories: contact with others, and methods of communicating, which will be discussed later in this chapter.

One participant explained why social networks were important to her:

“Yeah I think it’s really important for me [to have social networks] ‘cos otherwise I’d just sort of stay at home doing nothing (chuckles). Yeah it’s good to get out um and have that routine because otherwise like without the routine I think I really sort of need that routine”. (Participant #11)*

*Field notes indicate that this participant was seated comfortably on the couch and she was laughing when she expressed the above comment.

Another participant included checkout people [the people who operate the tills at supermarkets] as part of their social network. It was important to this participant to feel like he was known at the places he visits frequently:

“Well the checkout people. The chemist out here at [shopping centre] to get my tablets. Ran into [Health Professional B] while I was in the chemist shop. That’s about it”. (Participant #10)

Mental health professionals, family, friends, and church all form important social networks:

“The staff here; [Health Professional G]; Dr. [S]; [Health Professional P]; my friends in the church ...my fiancé; uhh friends at um [the clubhouse], even though I don’t go to [the clubhouse]; I don’t access [the clubhouse]. Friends that I talk to

over the phone or go downtown with; family; my brother's in [A town]; their family's in [A town]. My sister's in [N city]". (Participant #3)

"I've had contact with the mental health team, so I've seen the mental health nurse for my injections; I've seen you um I've seen the doctor – the psychiatrist and I think I've even seen my GP in the last month to get some scripts. So I'm fairly well covered in the medical and I'm not too badly covered with the friends and family either. So I'm starting to get a balance what works in my life. Yeah, 'cos I understand I can't see someone all the time, you know, they've got their own family things to do or their own things to do but it's nice to just appreciate the time with them when I can". (Participant #1)

In addition to family and health professionals, the participant below also added work colleagues as a vital part of his social network:

"...Dr [S] and Dr [SH], um my GP. He's also really good...work colleagues. Um there's a small group of work colleagues that I have there. It's only a small business so um, a few friends; Mum, my brother. My brothers um; my family, yeah". (Participant #4)

Forrester-Jones, Carpenter, Coolen-Schrijner, Cambridge, Tate, Hallam, Beecham, Knapp and Wooff (2012:10) investigated the social networks of adults living with severe mental illness in the community. These authors found that adults living with severe mental illness have smaller social networks compared to the general population. These was similar to the findings of this present study as the majority of the participants had small social networks and social networks relied heavily on mental health professionals. Amongst individuals living with severe mental illness, it has been noted that their social networks consist mostly of relatives and as their illness progresses, their social networks appear to comprise of other mental health consumers (Albert et al 1998:249). Meeks and Murrell (1994:399) also found that the social networks of those living with a severe mental illness were smaller, less reciprocal and contained fewer family members. Social networks were likely to include service providers.

Some of the participants identified a local clubhouse and other community groups as being important social networks for them, and a place where they could acquire social skills:

*“Ahh I went to [the clubhouse] and I learnt how to cook in there. Well, I contributed in the kitchen and eventually learned how to cook quite a lot better”.
(Participant #2)*

“...I found another group in [T town] actually um at [a community centre]. And the woman that runs that has actually set up a support group. And I’ve started going to that once a week and that’s quite interesting as well... I’ve joined the heart foundation walking group twice a week and I would like to do that every morning but they don’t do that every morning. And they are a really lovely group of women. And then sometimes, what they started doing now is after the walking group they go and play tennis...” (Participant #6)

An intentional recovery programme such as the clubhouse model has been found to foster social connections in individuals living with severe mental illness who are at risk of social isolation. They form an important part of the social networks of those living with severe mental illness and become a means of social support for them by giving them a place to belong and to contribute. The clubhouse provides opportunities for those living with severe mental illness to meet individuals in similar situations and have contact with others in similar contexts (Corolan, Onaga, Pernice-Duca & Jimenez 2011:125).

Participation in community groups, being involved in intimate relationships and social networks, have been found to increase one’s chances of accessing various forms of support which in turn protects and acts as a buffer against emotional distress (Kawachi & Berkman 2001:460). Contact with others is further discussed below.

4.8.1 Contact with others

In the present study ‘contact with others’ referred to how often the participants saw, engaged with, or interacted with other people in their world.

Some of the participants had minimal contact with others while other participants had a lot of contact with others. Those participants who had minimal contact with others expressed how they preferred their own company:

“Ahh um well I’m still by myself a lot. Um I’m happy having limited contact with people. Hehe. I’m a bit of an introvert when it comes to dealing with crowds and people”. (Participant #12)

“No I’m not a member of any clubs. I have very little social network; no, but it doesn’t bother me that much”. (Participant #2)

Although the participants above expressed that they preferred their own company, this may have been a self-preservation measure due to past experiences of being rejected or stigmatised. Research has shown that mental illness has been identified as the least accepted disability in social relationships. This results in greater social distance and fewer friendship opportunities (Gordan, Tantillo, Feldman & Perrone 2004:50).

One participant discussed how they did not consider themselves a social person but when they did have opportunities to socialise with others, they really enjoyed it:

“Well there’s the computer, there’s bowls and- not many social networks actually um eh... As I said, I’m not that social a person. Oh I go to parties sometimes or wakes, funeral wakes for members of my family, distant family that have died. The thing is, the paradoxical thing is as much as I don’t like socialising, when I get out there and socialise, I, I really have a ball”. (Participant #10)

Another participant described how her volunteer work gave her a sense of purpose because she was contributing:

“...In the last month I’ve started volunteering at the art gallery and I find that very rewarding. It’s great to have this sense of um... you know, going to work and do doing something where you feel valued even if you’re not being paid”. (Participant #6)

The participants who had frequent contact with others, had a number of different social networks. These social networks consisted of friends, health professionals, and online social network sites:

“Um my friend [Mr M], my daughter... part time partner, um my friend [Miss D] down at [the clubhouse], um... I got a friend [Miss HM] who’s been keeping in contact... just various friends... [Health Professional A] from mental health, [Health Professional H] from mental health, um... went to the ladies group the other day for a little while”. (Participant #8)

“The social networks currently are my 2 best friends, interactions with them and doing things with them and and the online ones. Facebook and a couple of chat rooms that I visit. Um psychiatrist here, my GP, ah... I did have any email from my case worker and a quick phonecall before she moved on... my work colleagues and clients”. (Participant #5)

Social networks also consisted of family and community groups:

“... Probably my two friends and my mum and my Dad and step-mum ... and... like I go to orchestra so those people. And I go to guides so all those people (chuckles). Um... I think I’ve also been- in the last month I’ve been playing in a musical, so pretty much all those people (chuckles) um and probably my psychologist too. Um I do go to a social group on a Thursday which at [community centre] called the [B] group um so I go there every week”. (Participant #11)

Albert et al (1998:248) found that individuals living with severe mental illness have smaller social networks compared to the general population. The participants in the present study are from a lower socioeconomic group. Individuals from a low socioeconomic status have been found to have smaller social networks and poorer levels of social support (Smyth et al 2015:1111).

Supportive social interactions with others have been found to be related to a higher quality of life for individuals living with severe mental illness whereas negative social interactions are related to a lower quality of life. Negative social interactions that are

stigmatising in nature also significantly impact mental health consumers' quality of life (Yanos, Rosenfield & Horwitz 2001:405).

One participant discussed how he started attending a prayer group. From this prayer group he was able to develop some relationships that broadened his social network and as a result he was able to complete different social activities with a number of different people:

"I see a prayer group. There's about four or five people there plus a priest. Every Wednesday we go to a prayer group. Um also I see a friend to go and watch movies from the prayer group. We go to the movies so we've been to the movies once this month. I've seen my brother and his family, this month. Um I've seen another brother and his family this month um where we've had a meal with him and talked to him; spent time with him. Ahhm I've seen another friend that comes around and wants to go fishing with me and um yeah we want to play cards together and that sort of stuff. I see another friend that I go for coffee with on a Monday and he's a good support". (Participant #1)

The women in this study were found to have more diverse social networks when compared to the men in the study. This is similar to the findings of Müller et al's (2007:571) study that discovered that participants without close friends perceived less support while those with a partner and friends found them very supportive, which is similar to the findings of this present study.

Although Albert et al (1998:248) claim that smaller social networks were associated with more frequent hospitalisation, the findings from this present study were inconclusive.

The participants used a number of methods to communicate with their social networks. These methods of communicating are discussed below.

4.8.2 Methods of communicating

The participants identified different ways that they communicated with their friends, families, and loved ones. The different methods of communicating include: face-to-face,

phone, SMS, Facebook, and talk-back radio. These various methods of communicating were an important part as to how the participants accessed their social support.

The most common method of communicating used by participants, was the phone:

“Phone, SMS or telephone, yes I use that a fair bit. I rely on the phone a fair bit and um sometimes I Just run into them down the street so by chance but mainly phone”. (Participant #1)

“I talk to my daughter every day, yeah and my friend in [N city] every day... nearly every day. My friend [Miss D] quite often and [Miss HM] quite often um... I ring other people too and they ring me occasionally... it's not a great deal of people really. (Participant #8)

“Mostly it's telephone but if or or person to person if people are in town. Um... yes I might ring up [Miss J], pop round and visit her or um I ring up my sisters and go with her into town, we might go and have lunch. I haven't seen them, oh I did see one sister two days ago. We had lunch. And... as another twin, my twin sister um I haven't seen her for a couple of weeks. But I have spoken to her on the phone and I spoke to my other sisters on the phone. Ah... but otherwise I'll go shopping and I'll talk to the sales people”. (Participant #6)

“Umm I ring my brother every night; I ring my sister every night. I ring my other brother's family once every few days. I ring my Aunty[X]; she's 98 and she's in a nursing home. I ring her once a week. I ring my nieces. I ring my nephew once a week. Yeah, so I'm constantly on ... but I've got a really good plan”. (Participant #3)

Other methods of communicating identified by participants included text messages, Facebook messages, or face-to-face contact.

“Usually just either text messages or Facebook messages. My Dad rings up probably every week or so um so I get to talk with them. Um, my mum Facebooks me probably at least once or twice a week. I get a bit anxious using like talking on the phone but I use it if I have to”. (Participant #11)

Participant #11 disclosed that she felt anxious when using the telephone so she felt more comfortable communicating with other by Facebook messages or text messages.

Participant #8 was the only participant who identified that one of her methods of communicating was talk-back radio.

“And I don’t do Facebook or anything like that...I get on the radio quite often at night that’s what I was doing last night”. (Participant #8)

This participant explained how they used the telephone and sending text messages to get their support:

“Umm I’m not on Facebook or anything like that but I telephone people and I SMS people so that’s how I get most of my support”. (Participant #1)

The methods of communicating identified by the participants present an opportunity for mental health services to use mobile-phone-based and internet-based interventions. All the participants in the present study owned a mobile phone and reported using it daily, either to make phone calls or to send text messages, while some participants reported owning a computer and using the internet. The present study’s findings were consistent with the results of Carras, Mojtabai, Furr-Holden, Eaton and Cullen (2014:94), who found that among mental health consumers attending a community mental health service, the majority owned mobile phones and used them daily. Some of the participants reported to owning a computer and using the internet to access social media sites, health information and email.

The conclusion of the chapter follows next in the form of a conceptual map.

4.9 CONCLUSION

The themes, categories and sub-categories were used to develop a conceptual map. (Refer to Figure 4.1 for conceptual map).

Physical health impacting on mental well-being and symptoms of mental illness is linked to the first person to notice symptoms and is associated with a person’s first contact

with mental health services along with hospital admission. Hospital admission is, in turn, part of the support provided by mental health services. The first person to notice symptoms is a part of relationships. Four types of relationships were identified: relationship with children, relationship with partner, relationship with friends, and relationship with health professionals. The relationship with health professionals is a part of the support received from mental health services. Relationship with friends is a part of contact with others which, in turn, is a part of the emotional support received. Contact with others is linked to methods of communicating and social networks. Social support was broken down to emotional support, physical support, and emotional support. Family attitudes towards mental illness form a part of attitudes towards mental illness and society's attitude towards mental illness. Family's attitude towards mental illness, therefore, impacts social support. Attitudes towards living with mental illness affect a consumer's attitude towards mental illness and their seeking help and response to medication. This is also linked to the influence to use mental health services which is connected to the first contact with mental health services. Seeking help is associated with support from mental health services and is related to the use of medication.

This chapter discussed the research findings and analysis. Major themes, categories and sub-categories that emerged from the data was tabled and discussed. A conceptual map which captured the findings, also emerged.

Chapter 5 concludes the study, makes recommendations for practice and further research, and discusses the limitations of the study.

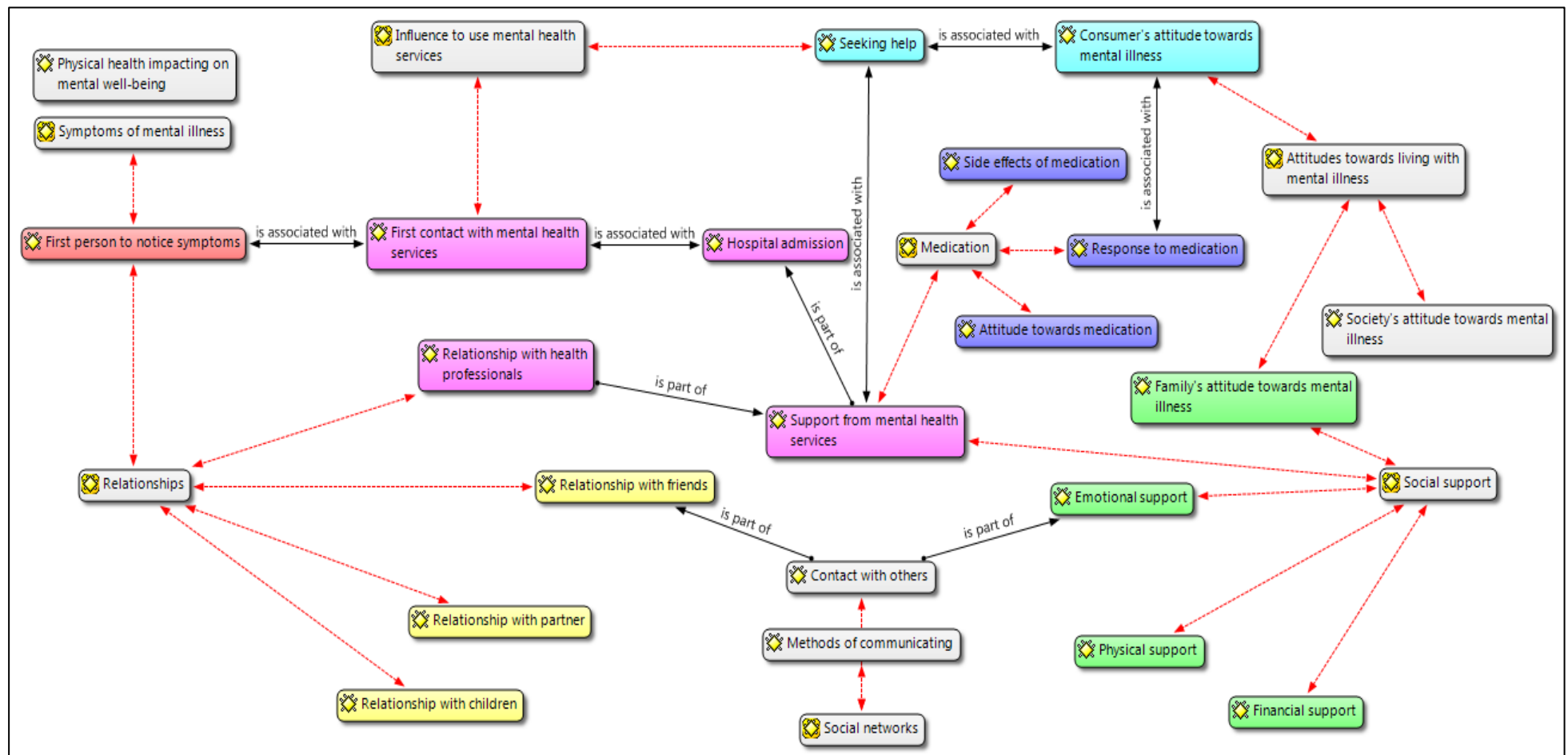


Figure 4.1: Conceptual map of themes, categories and sub-categories

CHAPTER 5

CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

“The road is long with many a winding turn. That leads us to who knows where’ as sung by The Hollies. Indeed it has been a long journey. I hope the findings of this study will make positive changes to practice and policies which will improve the services provided to mental health consumers and ultimately their quality of life”. (extract from reflective journal: 01/02/2016)

5.1 INTRODUCTION

Chapter 4 described the data analysis, interpretation and presentation of the results. The themes, categories and sub-categories that emerged were discussed in detail. This chapter concludes the study by reflecting on the major findings, providing conclusions and recommendations for practice and further research, and by discussing the limitations of the study.

The aim of this study was to enhance the understanding of the role that social networks and social support have on mental health service utilisation by mental health consumers in rural New South Wales.

The research findings were able to address the research objectives in the following ways:

Objective one: To establish what social networks mental health consumers utilise.

The data for this objective was based on the findings from the interviews with the participants. Chapter 4 discussed these findings in detail (Refer to Annexure B for interview guide and Annexure I for an example of an interview transcript). The findings were able to identify that the social networks that mental health consumers use include family, friends, and health professionals. Other social networks that were identified

included church, community groups, shop assistants, and online friends through Facebook and chatrooms.

Objective two: To explore and describe the perceived support that social networks provide to mental health consumers.

The participants identified that their social networks provided them with four types of social support. Firstly they described emotional support which they saw as talking to friends and family who are concerned about their well-being. Secondly, participants described physical (instrumental) support which they defined as the practical help that was offered to them by family or friends. This included cooking meals, facilitating hospital admission, looking after their property while in hospital, and mowing the lawn. Thirdly, participants described financial support which they defined as family or friends giving or lending them money. Finally, participants described the support they received from mental health services. They identified that this support provided safety for them, assisted them with practical tasks, monitored their mental well-being and activities of daily living, including being employed.

Prior to the commencement of the present study, the researcher identified that little research in recent years pertaining to social networks and social support and how they impact mental health service utilisation, especially within the rural context, had been conducted. The researcher also identified that no previous studies investigating the role that social networks and social support have on mental health service use have been conducted in rural New South Wales. As such, the researcher was able to bridge this research gap by conducting the present study. The researcher was able to identify what social networks and supports exist and how contact with social networks and having social support affects mental health service utilisation by mental health consumers. The findings from the present study identified that within the rural context of New South Wales, mental health consumers make use of mental health services more as a result of having a social network which provides them with social support.

Objective three: To explore and describe the influence of social networks in the decision-making process to utilise mental health services.

The research findings indicated that when mental health consumers were involved in the decision-making process whether or not they should utilise mental health services, there were three major influences. The first influence was the influence of health professionals, followed by the influence of family and friends. Finally, the consumers themselves would make the decision to utilise mental health services. The decision to use mental health services was linked to the influence of social networks. The major influence of social networks appeared to be health professionals as they formed a large part of the participants' social networks. All the research participants were linked with a case manager from their local community health team, and this influenced their decision to use mental health services. Some of the participants identified that they independently made the decision to utilise mental health services. Other participants said that their decision to use mental health services was influenced by family and friends. Families and friends were often responsible for accompanying the participants to see general practitioners, mental health professionals, and also by facilitating hospital admissions.

Objective four: To make recommendations for health care workers to enhance the role of social networks in mental health service utilisation.

In order to address this objective, the researcher made a number of recommendations that were identified from gaps in the literature and information provided by the participants. These are discussed in Section 5.3 under recommendations.

To address the research questions and meet objectives, a generic qualitative design that is explorative and descriptive in nature was used. This is also known as a descriptive qualitative study.

The study was completed in the northern region of New South Wales which is also known as the New England North West Regions of New South Wales. The target population from which the research participants were recruited were adults from a rural or regional area of New South Wales who have a diagnosis of mental illness and have accessed mental health services. The researcher made use of purposive sampling and

then moved onto convenience sampling in order to select research participants. Participants who were willing and available were included in this study. Potential participants for the study responded to flyers (Refer to Annexure A) that provided a brief description of the study and contact information for the researcher. Potential participants were also recruited through the assistance of local mental health services. The participants who met the inclusion criteria were included in the study (Refer to Chapter 1 and Chapter 3 for further details).

Data was collected through semi-structured interviews in a place the participants felt most comfortable, which was usually their own homes. Informed consent was obtained and all other permissions were also obtained. The interviews were audio-recorded and data was collected until data saturation had occurred after 12 interviews. Data collection and analysis occurred simultaneously during the study. The researcher firstly made use of open coding to organise the raw data. The researcher then moved onto thematic analysis in order to analyse data.

A reflection on the research findings follows next.

5.2 REFLECTION ON FINDINGS

Twelve participants took part in the research. Six of the twelve participants were male (50%) and the other 50% were female. Most of the participants were single (66.7%). Three participants were divorced (25%) and one participant was married (8.3%). The participants' ages ranged from 28 years to 62 years. The mean age was 43.6 years. Most of the participants were unemployed (75%) while three (25%) were employed part-time. Seven participants had completed tertiary education (58.3%), two completed grade 12 (16.7%), one completed grade 8, one completed grade 10 (8.3%) and one completed grade 11 (8.3%). The most common diagnoses were Schizophrenia (33.3%) and Bipolar Affective Disorder (33.3%). These were closely followed by Schizoaffective Disorder (25%) and one participant had a diagnosis of Major Depressive Disorder (8.3%). Participants' stay in a rural area ranged from one year to 44 years. The mean stay was 22 years. The majority of the participants lived alone (91.6%) while the one married participant (8.3%) lived with her husband and four children.

The reflections were drawn from the following research questions:

1. What kind of social networks are predominantly used by mental health consumers?
2. How are social networks perceived as supportive measures by mental health consumers?
3. How do social networks affect the use of mental health services by mental health consumers?
4. What is the role of social networks in mental health service utilisation?
5. What can be done to enhance the role of social networks?

Each of the five research questions will be discussed individually and how the findings of the present study served to answer each question. The findings were four themes (relationships, living with mental illness, social support, and social networks), sixteen categories (relationship with partner, relationship with children, relationship with health professionals, relationship with friends, symptoms of mental illness, medication, attitudes towards living with mental illness, hospital admission, influence to use mental health services, physical health impacting on mental well-being, emotional support, physical support, financial support, support from mental health services, contact with others, and methods of communicating) and four sub-categories (first person to notice symptoms, family's attitude towards mental illness, consumers' attitude towards mental illness, and society's attitude towards mental illness).

5.2.1 Research question one: What kind of social networks are predominantly used by mental health consumers?

This research question was addressed under the theme of 'social networks' with two categories which were 'contact with others' and 'methods of communicating'. The category of 'contact with others' was able to identify what kind of social networks were mostly used by mental health consumers. The findings identified that health professionals, family, friends, community groups, the clubhouse, and online friends through chat rooms or Facebook form part of the social networks of mental health consumers. All of the participants in the study were linked with a case manager from their local community mental health team. Each participant explained how their case manager formed an important part of their social network. The majority of the participants described how they had at least one close friend or acquaintance they

spent time with. Only three of the participants expressed that they preferred their own company and so did not report many friends. A third of the participants indicated that they were part of community groups or the clubhouse which helped get them out of the house and involved in community activities which were an important part of their social networks. A few participants advised that they used online chat rooms and Facebook as part of their social networks. The majority of the participants identified that family were an important part of their social network. However, only 50% of the participants had regular contact (at least once a week) with their family members. The other half of the participants appeared to have more regular contact with friends or acquaintances than family members.

With regards to 'methods of communicating' the participants identified a number of different ways that they communicated with their friends, families and loved ones. The various methods of communicating included: face-to-face, phone, SMS, Facebook, and talk-back radio. These different methods of communicating were an important part as to how the participants accessed their social support from those who formed part of their social networks. The most common method of communicating used by participants was the phone, either by making phone calls or sending text (SMS) messages.

5.2.2 Research question two: How are social networks perceived as supportive measures by mental health consumers?

The research findings indicated that participants perceived four types of social support from social networks. Firstly there was emotional support. The participants relied on their friends and family for emotional support. Occasionally, a participant would rely on their mental health case manager for emotional support. Second was physical (instrumental) support. This was the practical help provided by friends and family. It included cooking meals, mowing the lawn, looking after their property while in hospital, and practical support such as moving items. An important part of physical support is financial support. Financial support was described by the participants as family and friends lending or giving them money. Financial support was also seen as family and friends buying them items that they were in need of, such as cigarettes. Financial support was also received in the form of the disability support pension (DSP), although this was only explicitly expressed by one participant. Finally, the participants described the support they received from mental health services. Mental health services were

responsible for providing the following support: medication monitoring, monitoring mental state, and education regarding living with a mental illness. Some case managers assisted the participants with practical tasks such as shopping.

5.2.3 Research question three: How do social networks affect the use of mental health services by mental health consumers?

Research question three and four **What is the role of social networks in mental health service utilisation?** were integrated into one question as they were linked by the findings that emerged.

Findings indicated that social networks influenced the use of mental health services. Under the theme 'living with mental illness' is the category 'influence to use mental health services' which highlights the influences on mental health consumers' use of mental health services. There was a professional and a personal influence to use mental health services. Since health professionals formed a large part of the participants' social networks, health professionals were able to influence mental health consumers to use mental health services. This included arranging appointments, monitoring mental state, and facilitating hospital admissions when required. Some of the participants described personal influence, where they were the ones who independently made the decision to use mental health services. Other participants explained how their decision to use mental health services was influenced by family or friends. Family or friends were responsible for contacting GP's and discussing the mental health consumer's mental illness. Family and friends were also responsible for arranging the ambulance when a mental health consumer was unwell, and facilitating a hospital admission to a mental health unit.

5.3 RECOMMENDATIONS

Recommendations were formed based on findings that emerged from the data and literature review, and were based on the following research question:

5.3.1 Research question five: What can be done to enhance the role of social networks?

The answer to this research question follows with mention of how the role of those who form part of mental health consumers' social networks can be enhanced:

- The findings identified that the social networks of mental health consumers consisted of family and friends. Studies have shown that families and carers want to be integrally involved in the decisions that affect the care of their loved ones living with mental illness. Families have identified that they require greater transparency and consultation with mental health professionals (Jewell 2012:44; Rowe 2012:70). It is therefore recommended that social networks (family and friends) should be integrally involved in the care of mental health consumers as they are the ones that provide social support and are often responsible for facilitating mental health consumers' contact with and use of mental health services.
- Burnout, especially in families, was identified as a result of the participants living with mental illness. Caring for a person living with a severe mental illness places burdens on families, leading to burnout (Weimand, Hall-Lord, Sällström & Hedelin 2013:99). Some family members exhibited negative attitudes towards the participants and towards mental illness in general, impacting on the social support they are able to provide. Family members have been found to both facilitate and impede recovery for those living with severe mental illness (Aldersey & Whitley 2015:467). Families facilitate recovery by providing practical and emotional support. Families impede recovery through displaying stigma and lack of understanding. This stigma was presented by family members avoiding the person living with severe mental illness, being ashamed of the person living with severe mental illness, and hiding that a family member is living with a severe mental illness from extended family (Aldersey & Whitley 2015:467). Studies have found that families and carers would benefit from education and support from mental health professionals in order to be able to support their relatives living with severe mental illness. This support will further assist in preventing mental distress and burnout in carers and family members (Levy-Frank, Hasson-Ohayon, Kravetz & Roe 2012:265; Sintayehu, Mulat, Yohannis, Adera & Fekade 2015:1; Svetlini, Johnson, Magro, Saunders, Jones, Silk, Hargarter & Shreiner 2015:472). In light of this, it is therefore recommended that family members

who play an important role and form part of social networks of mental health consumers, be provided with support, education and be linked with other services that specifically support families. Education and support can be provided by local mental health services through the use of peer workers. Education and support can also be provided by community managed organisations (CMO's) such as Carer Assist, who provide specific support for those caring for people living mental illness.

- Some of the participants identified that community managed organisations (CMO's) formed a part of their social networks. The support provided by community managed organisations includes supported employment, education, family and carer support, rehabilitation, social inclusion, recovery, and relapse prevention. Literature has identified that partnerships between CMO's and mental health professionals need to be strengthened in order to improve the outcomes of those living with severe mental illness in the community (Hungerford, Hungerford, Fox & Cleary 2016:350). It is recommended that education is provided to CMO's regarding how to support mental health consumers and when to refer to mental health services. This education is best provided by the local mental health services to the specific CMO's that they liaise with. These examples include Centacare, Flourish Australia, and Benevolent Society.
- Studies have found that mental health consumers lack computer skills and access to computers. This impacts mental health consumers' ability to complete computerised intervention programmes and participate in online support groups and forums (Wright-Berryman, Salyers, O'Halloran, Kemp, Mueser & Diazoni 2013:231; Zamani, Smith & Monk 2013:1). The findings of the present study highlighted that some of the participants had poor computer literacy. As such, very few of the participants accessed the internet for information resources or as a means to access social support. It is therefore recommended that opportunities be created where mental health consumers can access training or teaching of computer skills so as to be able to increase their access to online friends, mental health resources, and support groups. CMO's are best placed to facilitate these opportunities by linking mental health consumers with local community colleagues or TAFE where basic computer courses are provided. Some local CMO's also offer computer training as part of their service.

5.3.2 Recommendations for health professionals and mental health services

The recommendations for health professionals and mental health services will discuss collaboration with mental health consumers, addressing physical health concerns of mental health consumers, education for other service providers, addressing medication side-effects, targeting stigma, managing trauma, and identifying intimate partner violence.

- The findings identified that mental health consumers want health professionals to show a genuine interest in their well-being. The research findings and results from other studies also highlighted that mental health consumers want to be integrally involved in the decisions that affect their care and treatment (Bennetts, Cross & Bloomer 2011:155; Clossey & Rheinheimer 2014:427; Sohn, Barrett & Talbert 2014:922). It is therefore recommended that the management of mental health services implement policies that would improve communication between mental health consumers and health professionals and enhance collaboration. These policies should be updated every 3 to 5 years. Implementation of such policies should form part of staff training and orientation. Health professionals need to treat mental health consumers with respect and value their contributions (Bennetts et al 2011:155; Clossey & Rheinheimer 2014:427; Sohn et al 2014:922). A number of participants identified loneliness as contributing to their mental illness. It is recommended that mental health professionals need to be aware of this loneliness and collaborate with mental health consumers with regards to how to target loneliness within their lives. This collaboration should form part of case management.
- The participants identified that they would like mental health professionals to address their physical health concerns. The literature extensively discusses the risk to mental health consumers' physical health from both the lifestyle that those with severe mental illness often live and the side-effects of psychotropic medications (Happell, Stanton, Hoey & Scott 2014:114; Happell, Scott, Platania-Phung & Nankivell 2012:202; Stanley & Laugharne 2011:824). Studies clearly indicate that the physical health of mental health consumers should be a priority and should be included as part of collaborative care planning (Happell et al 2014:114; Happell et al 2012:202; van Hasselt, Oud & Loonen 2015:387; Stanley & Laugharne 2011:824). Other studies have identified that a nursing position based in local community mental health

teams dedicated to physical health and coordination may improve the outcomes for mental health consumers (Happell, Ewart, Platania-Phung, Bocking, Griffiths, Scholz & Stanton 2016:377; Happell, Platania-Phung & Scott 2014:11; Happell et al 2014:114). It is recommended that mental health services should address the physical health concerns of mental health consumers. This includes brief screening of risk factors for common physical health problems. Education for mental health professionals needs to be provided with regards to the basic screening required when mental health consumers are being treated and how to engage with mental health consumers around these risk factors, and when and where to refer for further assistance. Education can be provided through regular in-services by generalist health services, senior mental health clinicians, or external service providers. Mental health professionals in rural local mental health teams should include this as part of their collaborative care planning with mental health consumers.

- Participants identified that when they presented to their General Practitioner (GP) and emergency departments for physical health complaints, these were often ignored or overlooked on account of them having a diagnosis of a severe mental illness. Nash (2013:22) refers to this as 'diagnostic overshadowing'. 'Diagnostic overshadowing' occurs when symptoms of physical illness are attributed to a mental health consumer's mental illness. This increases the risk of treatment delay and the development of complications (Nash 2013:22). It is recommended that mental health services should educate and support generalist medical services in the adequate treatment of physical health complaints in those living with severe mental illness. This education can be completed through in-services by clinical nurse consultants, clinical nurse specialists or clinical nurse educators on each local rural mental health team.
- The literature identified that there need to be targeted anti-stigma campaigns in rural areas aimed at creating awareness and providing education (Hanisch, Twomey, Szeto, Birner, Nowaks & Sabariego 2016:1; Robinson et al 2012:308). This was identified as a great area of need by the participants. This was articulated by a participant who said *"...the bloody [town's] a clique small town. I know it's big but it's also very small. Everybody knows everybody's business"* (Participant #10). It was also further confirmed by Dharitri, Rao and Kalyanasundaram (2015:165), who found that people in rural communities have stigmatising attitudes towards mental illness.

Literature has further recognised that generalist health services have stigma towards those living with mental illness (Moll, Patten, Stuarts, Kirsh & MacDermids 2015:1).

Mental health consumers also experience significant self-stigma and stigma from family and friends (Hansson & Yanos 2016:1; Tsang 2013:4; Yanos, Luckstead, Drapalski, Roe & Lysaker 2015:171). Studies have also identified that many of the stigmatising attitudes that mental health consumers face come from mental health professionals. (Bayar, Poyraz, Aksoy-Poyraz & Arikan 2009:226; Li, Li, Thornicroft & Huang 2014:1). In light of this, it is recommended that mental health services provide education for generalist health services in order to reduce stigma. It is also recommended that mental health professionals work with mental health consumers to reduce self-stigma and to target stigma from family members. Finally, it is important to recognise that mental health professionals themselves often stigmatise mental health consumers and it is recommended that mental health professionals target this within themselves.

- It has been extensively documented in literature that mental health professionals are highly prone to burnout and end up leaving their careers as a result of this, further perpetuating the shortage of mental health professionals (Lim, Kim, Kim, Yang & Lee 2010:86; Puig, Baggs, Mixon, Park, Kim & Lee 2012:98; Ray, Wong, White & Heaslip 2013:255; Volpe, Luciano, Palumbo, Sampogna, Del Vecchio & Fiorillo 2014:774). The present study highlighted that mental health professionals formed a large proportion of mental health consumers' social networks and provided support. It is therefore recommended that mental health services have policies and procedures that recognise that mental health professionals are prone to burnout and therefore need to have strategies for identifying burnout and pathways for professionals to access support. These pathways could include assessing the employee assistance programme (EAP) and policies to enforce that mental health professionals take leave entitlements at regular intervals in order to manage burnout.
- Studies have found that acute care teams provide effective care to mental health consumers whose needs are acute. This can further decrease hospitalisations by meeting the acute care needs of mental health consumers in their homes (Hoseyni Moosa, Qureshi, Ukpong & Singh 2010:628; Krishna, Alam & Jaganathan 2010:705). It is recommended that each mental health service consider the establishment of an

acute care team that is able to provide a 7 day a week service that conducts home visits to improve access to care in rural areas.

- Studies have highlighted the prevalence and increased incidence of intimate partner violence among those living with severe mental illness (Keshavan 2015:1; Trevillion, Agnew-Davies & Howard 2013:34). Other studies have identified the need for mental health services to provide training and education for mental health professionals with regards to how to screen for intimate partner violence and the appropriate referral pathways (Arkins, Begley & Higgins 2016:217; Nyame, Howard, Feder & Trevillion 2013:536; Trevillion et al 2013:34; Vinton & Wilke 2014:716). It is therefore recommended that mental health services have mandatory screening and educate mental health professionals with regards to available referral pathways for those living with intimate partner violence. It is also recommended that mental health services provide education and support for mental health professionals about how to work with victims and perpetrators.
- The majority of the participants disclosed that they had experienced a number of side effects as a result of taking psychotropic medication. Some of the participants found these side-effects distressing. Although the participants in the present study did not identify that experiencing side-effects affected their adherence to psychotropic medication, there is evidence in the literature to support this occurrence (Morrison, Meehan & Stomski 2015:104; Usher, Park & Foster 2013:801). It is recommended that mental health professionals be open to discussing side-effects of medication with mental health consumers and collaborate with mental health consumers regarding preferred medications. It is also recommended that mental health professionals advocate for a change in medication when a mental health consumer is experiencing distressing side-effects. Further to this, it is recommended that mental health services provide training and education to mental health professionals with regards to types of medications used to treat a variety of mental health diagnoses and the effects and side-effects of these medications.
- The participants identified that they experienced some difficulties in their relationships with their children. Often the primary care provider is a young person. Mental health services need to be aware that being a young carer is an established predisposing factor in the literature to the development of a mental illness in the

young person (Foster 2010:3143; Wansink, Drost, Paulus, Ruwaard, Hosman, Janssens & Evers 2016:1; Wansink, Janssens, Hoencamp, Middelkoop & Hosman 2015:110). It is therefore recommended that mental health services implement structured support and education programmes for children of parents with mental illness (COPMI) through local mental health teams and through collaboration with CMO's.

- Mental health consumers often experience trauma as a result of their acute in-patient hospital admissions. The literature identifies that practising with trauma-informed care can strengthen mental health professionals' knowledge and awareness of the association between a person's past history of trauma and the impact of this trauma on their mental illness. The aim of trauma-informed care is to avoid re-traumatising a mental health consumer during an episode of care. Education for health professionals may reduce the likelihood of re-traumatisation for mental health consumers (Berliner & Kolko 2016:171; Hall, McKenna Dearie, Maguire, Charleston & Furness 2016:1; Isobel & Edwards 2016:1). It is therefore recommended that mental health services recognise the impact of trauma on mental health consumers' experience and engagement with mental health services, especially during the acute phases of their illness, and implement policies and procedures for trauma-informed care.

5.3.3 Recommendations for further research

- Rural mental health services should investigate whether intentional friendship programmes would be beneficial to their mental health consumer group. Intentional friendship programmes aim to develop new social relationships for those living with severe mental illness by matching them in a one-to-one relationship with a community volunteer in order to complete weekly social activities (Corrigan & Sokol 2013:1; McCorkle et al 2009:291). These have been widely used in the USA (Corrigan & Sokol 2013:1) and most recently in urban areas in Australia (Sacca & Ryan 2011:439). Intentional friendship programmes have been found to be useful to teach social skills and improve social networks (McCorkle et al 2009:291).

- Further research should be conducted to investigate whether improving mental health consumers' computer skills increase their social networks and their access to social support.
- Further research should be conducted to assess whether structured Children of Parents with a Mental Illness (COPMI) programmes lead to improved relationships between those living with severe mental illness and their children.
- Further research should also identify whether structured COPMI programmes prevent emerging ill health in young carers.
- It would be beneficial for further research to determine whether the employment of those with a lived experience of mental illness within mental health services improves outcomes for mental health consumers within a services. These outcomes could include: admission rates, suicide attempts, and standardised measures.
- Research into whether the employment of mental health professionals improve the experience of mental health consumers who access emergency departments would prove to be beneficial.
- Further research is required with regards to how to provide a mental health service that utilises mobile phones and internet technology while remaining evidenced-based and effective.

5.4 LIMITATIONS OF THE STUDY

The researcher identified the following limitations in the present study:

- It takes some time to establish rapport with mental health consumers. The researcher met them for the first time, and this may have affected the quality of information gathered due to enduring symptoms of severe mental illness such as paranoia and mistrust. This was managed by the researcher conducting the interviews where the participants felt most comfortable. The researcher also provided clarity with regards to what information would be collected during the interviews and how this would be

used. The researcher was also able to establish rapport with the participants through maintaining eye contact, speaking clearly, having an open body posture, and by being warm and engaging.

- **Sample bias**

Sampling bias refers to the over-representation or under-representation of a segment of the population on a characteristic relevant to the study (Polit & Beck 2012:275). This study made use of purposive sampling and used maximum variation sampling to minimise the effects of sample bias by ensuring that different views were represented in the sample. However, the study may also have been subjected to self-selection bias as those who are most marginalised and most affected by the stigma of living with a severe mental illness, may have not wanted to participate in the study and therefore 'self-selected' themselves into a group that will not be investigated. Therefore, the results of the study may not represent their views (Landorf 2013:238-239).

- **Generalisability**

Qualitative researchers do not specifically seek to make their findings generalisable, but seek understanding that might prove useful in other situations (Polit & Beck 2012:180). The nature of the qualitative approach and the small sample size (12 participants) means that the results of the study cannot be generalised beyond the study population.

- **Recall bias**

The study may have been subject to recall bias as the participants were asked to recount their experiences retrospectively (Grove et al 2015:486). The cognitive effects of living with a severe mental illness may affect the accuracy of the information and also the type of information that was able to be collected. The communication techniques employed by the researcher, such as the use of open-ended questions and empathy, may have served to minimise the effects of this bias by assisting the participants to give a more accurate account of their experiences.

- **Researcher bias**

The researcher works within mental health services as an occupational therapist. As a result of this, the researcher may bring her prior knowledge and experience into the study. Bracketing is the process of identifying and suspending all prior ideas, beliefs or judgements so that the researcher is able to enter the world of the individuals whose experiences are the focus of the study (Carpenter 2013:117; Polit & Beck 2012:495). In order to overcome this problem of potential bias, the researcher kept a reflective journal throughout the study where her presuppositions were recorded in an effort to bracket. The researcher made entries in the reflective journal before the commencement of the study, after each interview, and in between interviews in order to have a record of the findings and her personal opinions, thoughts, feelings and biases. The use of peer review and the independent coder served to minimise this personal bias.

5.5 CONCLUDING REMARKS

This study employed a generic qualitative research design in order to discover the social networks and social support of mental health consumers within a rural context of New South Wales and how these social networks and social support influenced the use of mental health services. The findings of this study were discussed in detail in Chapter 4 and a conceptual map emerged summarizing the major themes, categories and sub-categories. The four major themes that emerged were relationships, living with mental illness, social support, and social networks. The themes highlighted the importance of relationships and how relationships with others formed the social networks of mental health consumers. These social networks, in turn, provided the social support required by mental health consumers. The impact of these social networks on the use of mental health services was also explored. What was important to note was that it was sometimes the mental health consumers themselves who made the decision to utilise mental health services, at other times it was the influence of their social networks (family, friends and health professionals).

A number of recommendations emerged which were divided into three areas. Firstly are recommendations that focused on how to enhance the role of social networks. Secondly are recommendations for mental health services and mental health professionals. Finally, there are recommendations for areas of further research. Due to the small

sample size, the results of this study cannot be generalised beyond the study population. However this study has provided some useful insights that can help improve the care of rural mental health consumers.

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ANNEXURES

ANNEXURE A: FLYER FOR MENTAL HEALTH CONSUMER



Dear mental health consumer

1. Are you between the ages of 18 and 65 years?
2. Are you currently mentally stable and not hospitalised?
3. Have you lived in a rural or regional area of New South Wales for longer than six months?
4. Do you have a diagnosis of a severe mental illness?
5. Would you be willing to be interviewed for an hour on how use mental health services and the social supports you have in your life?

If you have answered **YES** to any of these questions they you may be suitable to participate in a study that is seeking to look at Social Support and how you use mental health services as a consumer.

If you are interested in knowing more information.

Please contact your case manager or reception and they will give you an information pack which will give you more information about the study and who to call for more information and questions.

ANNEXURE B: TOPIC GUIDE



Interview Guide: The role of social networks and social support on mental health service utilisation by mental health consumers in rural New South Wales

Service user I.D.

Social demographic data

Age:

Gender:

Marital status:

Education level:

Language and literacy skills:

Employment status:

Occupation before becoming ill:

Place of birth:

Length of stay in rural or regional area:

Post code:

Living status:

Mental Health History

Diagnosis:

Person giving the diagnosis:

Interview Guide: The role of social networks and social support on mental health service utilisation by mental health consumers in rural New South Wales

1. How did you first come into contact with mental health services?

Use the following prompts if necessary:

- What was the help-seeking experience like?
- When did you first notice you were unwell?
- How did you respond?
- Who was the person who first noticed the symptoms?
- What did they do?
- When did you start to seek help?
- Who was the first person you talked to about your problem?
- Why did you choose to talk to this person?

2. What is the role that health professionals have played or play in your experience of seeking help for your mental illness?

3. What is the role that other people have played or play in your journey of seeking help for your mental illness?

Use the following prompts if necessary:

- Who are those people?
- How did they become involved?
- What role did these people play in your visiting mental health services?
- Who helps you decide when to visit mental health services?

4. Identify as many people as you can think of that you have had any contact with in the last month.

Use the following prompts if necessary:

- Think of the people who made you feel good.
- Think of the people who made you feel badly.
- Think of people who played an (important) part in your life.
- How often do you communicate with family/ friends?

- What means do you use to communicate with family/friends/people close to you (face to face; skype, phone, email, post)?

5. If you were in trouble is there someone in your life that you can turn to?

Use the following prompts if necessary:

- How can you tell that the people in your life really care about you?
- How do you know they will be there for you if you need help?
- What support do they provide to you?
- Who can you trust with your most private thoughts and feelings?

Other optional questions:

- What support do you need?
- What support do you get?
- What does support look like to you?
- What social networks do you have?
- What social networks would you like?

ANNEXURE C: INFORMED CONSENT



The role of social networks and social support on mental health service utilisation by mental health consumers in rural New South Wales

PARTICIPANT CONSENT FORM

I,[name] of
..... [address]
have read and understand that the study will be conducted as described in the Information Statement, a copy of which I have retained.

I understand that the interview discussion will be audiotaped, and I agree to this.

I understand that I am asked to participate in a research study that will look at what social networks I have in my life and how these affect the way that I make decisions whether or not to use mental health services.

If I agree to participate in the study I will be interviewed for approximately 60 minutes about my experience at a location I feel most comfortable.

I understand that my participation in this study will allow the researchers and others, as described in the Information Statement, to have access to my medical record, and I agree to this.

I agree to participate in this study and understand that I can withdraw at any time without providing a reason.

I understand that my personal information will remain confidential to the researchers.
I have had the opportunity to have questions answered to my satisfaction.

I hereby agree to participate in this research study.

NAME: _____

SIGNATURE: _____

DATE: _____

Declaration by person conducting the consent process

I, the undersigned, have fully explained this research to the patient named above.

NAME: _____

SIGNATURE: _____

DATE: _____

ANNEXURE D: CODING PROTOCOL

Liamputtong's (2013:245) eight- step method summarised from Bryman (2012) was used to code the data:

1. Coding should be commenced while the data is being collected to enable the researcher to have a better understanding of the data.
2. The initial transcripts, field notes or documents should be read without making any notes or attempting to interpret the data. After reading the data a few notes can be made regarding what appears important or significant.
3. The data should now be read again but this time the researcher should make marginal notes about significant observations or categories that emerge. The researcher may use key words expressed by the participants or give names to themes in the data (this is coding).
4. The researcher generates an index of terms that will assist with the interpretation of the data.
5. The codes should be reviewed and if there are two or more words or phrases relating to the same issue, one of them should be deleted.
6. The researcher should consider theoretical notions as it relates to codes and data and to outline connections between concepts and categories that are being generated. The researcher should also think about how these concepts relate to the existing literature.
7. The researcher should not be concerned about developing too many codes in the early stages of data analysis.
8. A piece of data may be coded in different ways so the researcher should look closely at the data to see if it can be coded differently.

ANNEXURE E: UNISA ETHICAL APPROVAL



**UNIVERSITY OF SOUTH AFRICA
Health Studies Higher Degrees Committee
College of Human Sciences
ETHICAL CLEARANCE CERTIFICATE**

REC-012714-039

HS HDC/359/2014

Date: 26 November 2014 Student No: 4803-781-8

Project Title: The role of social networks and social support on mental service utilization by mental health consumers in rural New South Wales.

Researcher: Sophia-Lorraine Noxolo Allie

Degree: Masters in Public Health Code: DIS4986

Supervisor: Dr E Janse van Rensburg
Qualification: D Cur
Joint Supervisor: -

DECISION OF COMMITTEE

Approved



Conditionally Approved



Prof L Roets
for CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE

L.O. Roets (Prof)

Prof MM Moleki

Prof MM Moleki
ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

ANNEXURE F: HUNTER NEW ENGLAND ETHICS COMMITTEE

APPROVAL



27 March 2015

Ms Sophia-Lorraine Allie
Occupational Therapist
Peel Community Mental Health Team
2/51 Rawson Avenue
Tamworth NSW 2340

Dear Ms Allie,

Re: The role of social networks and social support on mental health service utilisation by mental health consumers in rural New South Wales (15/02/18/4.09)

HNEHREC Reference No: 15/02/18/4.09
NSW HREC Reference No: HREC/15/HNE/46

Thank you for submitting the above application for single ethical review for a multi-centre study. This project was first considered by the Hunter New England Human Research Ethics Committee at its meeting held on **18 February 2015** and again on **18 March 2015**. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research (2007)* (National Statement) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review. The Committee's Terms of Reference are available from the Hunter New England Local Health District website.

I am pleased to advise that following acceptance under delegated authority of the requested clarifications and revised Participant Information Sheet by Dr Nicole Gerrand Manager, Research Ethics & Governance, the Hunter New England Human Research Ethics Committee has granted ethical approval of the above project.

The following documentation has been reviewed and approved by the Hunter New England Human Research Ethics Committee:

- For the Information for Participants (Version 3 dated 24 March 2015);
- For the Consent Form (no version, undated);
- For the Flyer (no version, undated); and
- For the Interview Guide (no version, undated)

For the study: **The role of social networks and social support on mental health service utilisation by mental health consumers in rural New South Wales**

Hunter New England Research Ethics & Governance Unit

Locked Bag 1

New Lambton NSW 2305

Telephone: (02) 49214950 Facsimile: (02) 49214818

Email: HNELHD-HREC@hnehealth.nsw.gov.au

http://www.hnehealth.nsw.gov.au/research_ethics_and_governance_unit

Approval has been granted for this study to take place at the following sites:

- **Mehi/McIntyre Mental Health Service, Moree and Narrabri**
- **Tablelands Mental Health Service, Armidale**
- **Peel Mental Health Service, Tamworth**

Approval from the Hunter New England Human Research Ethics Committee for the above protocol is given for a maximum of **3** years from the date of this letter, after which a renewal application will be required if the protocol has not been completed.

The *National Statement on Ethical Conduct in Human Research (2007)*, which the Committee is obliged to adhere to, include the requirement that the committee monitors the research protocols it has approved. In order for the Committee to fulfil this function, it requires:

- A report of the progress of the above protocol be submitted at 12 monthly intervals. Your review date is **March 2016**. A proforma for the annual report will be sent two weeks prior to the due date.
- A final report must be submitted at the completion of the above protocol, that is, after data analysis has been completed and a final report compiled. A proforma for the final report will be sent two weeks prior to the due date.
- All variations or amendments to this protocol, including amendments to the Information Sheet and Consent Form, must be forwarded to and approved by the Hunter New England Human Research Ethics Committee prior to their implementation.
- The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
 - any serious or unexpected adverse events
 - Adverse events, however minor, must be recorded as observed by the Investigator or as volunteered by a participant in this protocol. Full details will be documented, whether or not the Investigator or his deputies considers the event to be related to the trial substance or procedure. These do not need to be reported to the Hunter New England Human Research Ethics Committee
 - Serious adverse events that occur during the study or within six months of completion of the trial at your site should be reported to the Manager, Research Ethics & Governance, of the Hunter New England Human Research Ethics Committee as soon as possible and at the latest within 72 hours.
 - All other safety reporting should be in accordance with the NHMRC's Safety Monitoring Position Statement – May 2009 available at http://www.nhmrc.gov.au/health_ethics/hrecs/reference_files/090609_nhmrc_position_statement.pdf
 - Serious adverse events are defined as:
 - Causing death, life threatening or serious disability.
 - Cause or prolong hospitalisation.
 - Overdoses, cancers, congenital abnormalities whether judged to be

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caused by the investigational agent or new procedure or not.

- Unforeseen events that might affect continued ethical acceptability of the project.
- If for some reason the above protocol does not commence (for example it does not receive funding); is suspended or discontinued, please inform Dr Nicole Gerrand, as soon as possible.

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained.

A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.

Should you have any concerns or questions about your research, please contact Dr Gerrand as per the details at the bottom of the page. The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Please quote **15/02/18/4.09** in all correspondence.

The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully



For: Ms M Hunter
Acting Chair
Hunter New England Human Research Ethics Committee

Hunter New England Research Ethics & Governance Unit

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Health
Hunter New England
Local Health District

16 April 2015

Ms Sophia-Lorraine Allie
Occupational Therapist
Peel Community Mental Health Team
2/51 Rawson Avenue
Tamworth NSW 2340

Dear Ms Allie,

Re: The role of social networks and social support on mental health service utilisation by mental health consumers in rural New South Wales (15/02/18/4.09)

HNEHREC Reference No: 15/02/18/4.09
NSW HREC Reference No: HREC/15/HNE/46
SSA Reference No: SSA/14/HNE/137

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following sites:

- **Peel Mental Health Service**
- **Mehi/McIntyre Mental Health Service**
- **Tablelands Mental Health Service**

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer;
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer.

Yours faithfully

Dr Nicole Gerrand
Research Governance Officer
Hunter New England Local Health District

Hunter New England Research Ethics & Governance Unit

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New Lambton NSW 2305

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ANNEXURE G: LETTER TO SERVICE MANAGERS

2/51 Rawson Avenue
Tamworth
NSW
2340

20 April 2015

Dear Service Manager

**Re: Assistance in the recruitment of study participants for the following study:
The role of social networks and social support on mental health service
utilisation by mental health consumers in rural New South Wales.**

My name is Sophia-Lorraine Allie. I am a research student at the University of South Africa (UNISA) conducting research for the partial fulfillment of a **Masters in Public Health**. I would like to employ your assistance in the recruitment of study participants. Permission to undertake this research has been granted by the ethics committee at UNISA and also the Hunter New England ethics committee (Refer to ethics approval letters attached to this letter).

I have attached participant information to this letter which provides detailed information about the study. In summary, I am looking for study participants who:

- 1. Are between the ages of 18 and 65 years.**
- 2. Are currently mentally stable and not hospitalised.**
- 3. Have lived in a rural or regional area of New South Wales for longer than six months.**
- 4. Have a diagnosis of a severe mental illness.**
- 5. Would you be willing to be interviewed for an hour on how they use mental health services and the social supports they have in their life.**

I would like to request permission to place flyers for mental health consumers in your reception area and also to leave information about the study at reception so that those interested in the study may be able to access it.

I would also like to make an appointment with you so that I can provide information about the study in person and answer any questions or concerns you may have.

Thank you for your consideration in this matter.

I am contactable on **02 67677910** or email at:
sophialorraine.allie@hnehealth.nsw.gov.au.

Kind regards,
Sophia-Lorraine Allie

ANNEXURE H: PARTICIPANT INFORMATION



The role of social networks and social support on mental health service utilisation by mental health consumers in rural New South Wales

INFORMATION FOR PARTICIPANTS

Dear Prospective participant,

*My name is Sophia-Lorraine Allie. I am a research student at the University of South Africa (UNISA) **conducting research for the partial fulfillment of a Masters in Public Health.** I would like to invite you to take part in a research study. Before you decide it is important that you understand the reason for conducting this study and what it involves. Please take time to read the following information. If you want more information, please feel free to ask questions.*

What is the research about?

- This study aims to get a better understanding of your experience of mental health services and who influences your decision to use them.
- The study also aims to find out who you have in your social networks and the role that these people play in your life.

Where is the research being done?

The study is being conducted within this institution by Sophia-Lorraine Allie (Occupational Therapist Peel Community Health Service) as part of the requirements for a Masters in Public Health degree under the supervision of Dr Elsie Janse van Rensburg and Dr Alan Avery.

Who can participate in the research?

If you are an adult aged between the ages of 18 and 65 years , have a diagnosis of a severe mental illness (severe depression, bipolar affective disorder and schizophrenia) and have lived in a rural or remote region of New South Wales for longer than six months then you are invited to participate in the study.

If you are younger than 18 years or older than 65 years, do not live in a rural or remote area of NSW and do not have a diagnosis of a severe mental illness as diagnosed by a psychiatrist then unfortunately this study is not suitable for you.

What Choice do you have?

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without having to give a reason. Whatever your decision, please be assured that it will not affect your medical treatment or your relationship with the staff who are caring for you.

What would you be asked to do if you agree to participate?

If you agree to participate in this study, you will be asked to sign the Participant Consent Form. By agreeing to participate in the research you are agreeing to:

- Take part in a face-to-face interview.
- Each interview will last for about one hour.
- The interview will ask you to talk about your experience of mental health services and your social networks and social supports and how much contact you have with them.
- Notes will be taken during the interview.
- The interview will be audio-recorded if you agree. At any time during the interview you can ask for the tape to be stopped and the section of the interview be edited or erased. You will also be given a copy of the transcript of the interview to review. You may be asked to check what the information that was recorded at a later stage.

What are the risks and benefits of participating?

Risks

The interview may cause you distress and discomfort if you are asked to recall some of your experiences and they have been unpleasant or negative. You do not have to answer any questions or provide any information that makes you feel uncomfortable. If you do feel distressed or upset at any point, please inform the researcher. You may want to take time out of the interview or withdraw from the study. If you decide to withdraw from the study the interview transcript and recording will be destroyed. If you want to talk to someone else, you can contact your local community mental health team for further assistance. The researcher will provide you with more detail depending on your local area.

You may also contact the NSW Mental Health line which provides 24 hour mental health support. Their number is: **1800011511**.

Benefits

This study does not intend to help you as an individual. However, it is hoped that the study will improve the delivery of mental health services for other mental health consumers in future by providing information to policy makers to make mental health services more accessible to rural mental health consumers.

Will the study cost you anything?

Participation in this study will not cost you anything, nor will you be paid.

How will your privacy be protected?

All the information collected from you for the study will be treated confidentially, and only the researchers named above will have access to it. The study results may be presented at a conference or in a scientific publication, but individual participants will not be identifiable in such a presentation.

Your personal information will be accessed, used and stored in accordance with Commonwealth Privacy Laws and the NSW Health Records and Information Privacy Act 2002.

Should you wish to withdraw from the study, then your data will be withdrawn from the study also and will be destroyed.

Further Information

When you have read this information, Sophia-Lorraine Allie will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact her on 02 67677910 or email at: sophialorraine.allie@hnehealth.nsw.gov.au.

All the recorded materials will be used exclusively for the research purposes.

The recorded interview will be kept under lock and key in a safe place and will be destroyed after 15 years from the completion of the study.

Your identity will be kept anonymous and your name and personal information will not appear in any report.

Complaints about this research

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 15/02/18/4.09.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Manager, Research Ethics and Governance Unit, Hunter New England Human Research Ethics Committee, Hunter New England Local Health District, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, email Hnehrec@hnehealth.nsw.gov.au

AUTHOURISATION STATEMENTS

For HNELHD (for single site or site specific information statements done at HNELHD Sites)

The conduct of this study at the Peel Area has been authorised by Hunter New England Local Health District. Any person with concerns or complaints about the conduct of this study may also contact Dr Nicole Gerrand, Manager Research Ethics & Governance Unit on 4921 4950 and quote reference number **HREC/15/HNE/46**

ANNEXURE I: INTERVIEW TRANSCRIPT

Interview 1

Researcher: So how old are you?

Participant: 57

Researcher: 57... oh you're a spring chicken

Participant: oh no I don't feel like one

Researcher: and... are you married? Single?

Participant: divorced

Researcher: divorced... and what year did you get up to in school?

Participant: year... what do they call it over here? Year 8

Researcher: year 8? So around 14?

Participant: year 8... sorry... I was 15

Researcher: yeah... year 8

Participant: I didn't go to school here...

Researcher: where did you go to school?

Participant: in [Country N]

Researcher: oh ok so you're from [Country N]? Ok... when did you come to Australia?

Participant: in 1973

Researcher: oh that is a long time ago

Participant: it is a long time ago

Researcher: where were you born in [Country N]?

Participant: in [Y City]

Researcher: [Y City]?

Participant: south island yeah

Researcher: do you still have family there?

Participant: yeah

Researcher: ok... do you go and visit?

Participant: no... cause I'm frightened of flying...

Researcher: oh...

Participant: I haven't been there for a long time

Researcher: that's fair enough... and uh, what did you do before you became unwell?

Were you working?

Participant: ah, when I was married we had a transport business together

Researcher: oh ok

Participant: so I looked after a lot of things within the business... did a lot of hard work

Researcher: I bet you did

Participant: yeah I did

Researcher: so did you move to [T Town] in 1973?

Participant: yeah basically yeah

Researcher: ok

Participant: I can over with my family

Researcher: ok. So how long have you been here? 1973 oh that's a long time

Participant: so 2003 is 30 years... 40 years... 42 years I think

Researcher: ok. It's a long time... and you live alone?

Participant: yes

Researcher: ok

Participant: I've got a part time partner who comes over 1 or 2 or 3 nights a week
sometime

Researcher: (laughs) what's a part time partner?

Participant: (laughs) it means he's here part of the time

Researcher: (laughs) I like that

Participant: (laughs)... yeah... his name is [Mr R]

Researcher: ok

Participant: mmh...

Researcher: and he's got his own house?

Participant: yeah he's got his own flat over in south...

Researcher: ok... and um... so what's your diagnosis?

Participant: well I'm not really sure. They've originally said I had schizophrenia and I
think they still do ... um but Chris Brewer thought I might have had
schizoaffective disorder...

Researcher: mmh huh...

Participant: but anyway...

Researcher: so schizophrenia or schizoaffective disorder?

Participant: mmh huh...

Researcher: you're not on clozapine though?

Participant: no. there is some bipolar too. I don't know if their one and the same

Researcher: mmh...

Participant: no I'm not on clozeril thank goodness. I used to be and really knocked me
around... I hated it

Researcher: yeah... who gave you the diagnosis? Can you remember?

Participant: uuumm... probably Dr [T] or Dr [D] or Dr [B]

Researcher: ok

Participant: yeah... one of those 3

Researcher: were they just GP's?

Participant: no psychiatrists

Researcher: ok... and how old were you?

Participant: 38

Researcher: ok

Participant: remember it very clearly

Researcher: mmh... Can you remember how you first came into contact I guess with the with the mental health services?

Participant: yes... I I do... um my first contact was one afternoon... my ex-husband took me up there to [B Hospital]

Researcher: mmh huh...

Participant: so that he- he didn't have to worry about me for the afternoon

Researcher: oh ok

Participant: we weren't getting along well at the time either

Researcher: yep

Participant: um... yeah that was my first contact with with services... I mean I had-

Researcher: what year was that?

Participant: oh my first actual real contact was 1996

Researcher: mmh

Participant: my first contact was s'pose was in June of 1996, may june it was

Researcher: yep

Participant: with Dr [T]... yeah I ended up up at the base hospital for a night or two

Researcher: uh huh...

Participant: and um... I was very concerned about the kids... cause I- at that point I was fearful of my husband

Researcher: mmh...

Participant: and I thought that he might hurt the kids and I didn't want to be up there at the hospital

Researcher: mmh

Participant: wanted to be home with my kids

Researcher: was was your husband abusive?

Participant: he was towards me

Researcher: ok

Participant: not to the kids normally... but I in my state of mind at the time I um thought that they were gonna get hurt. And also I didn't believe that I was ill... at the time. Um and Dr [T] agreed with me at the time that I was well enough to go home

Researcher: mmh... so what were the first symptoms that you noticed I guess?

Participant: well um... I can tell you how I felt back then

Researcher: yeah...

Participant: but there was no diagnosis for quite a few months and no medication

Researcher: so how did you feel?

Participant: um... my thoughts were racing

Researcher: mmh huh...

Participant: I had a lot of paranoia

Researcher: yep

Participant: um... I saw a lot of strange things in my mind

Researcher: mmh huh...

Participant: um... and I still remember quite clearly like aboriginal dancing in a circle and all sorts of things... it was very frightening... you used to hear a lot of hear voices. When I was driving around out here I'd hear a voice all the time. I was hearing voices... um... at that time... um... that went on for quite a few months

Researcher: mmh...

Participant: and my GP put me on a medication that really didn't help... it was prothiaden

Researcher: mmh huh...

Participant: and that didn't help the voices and all that

Researcher: mmh...

Participant: um I'm not sure if it was the wrong medication... that was before I ended up seeing the psychiatrist on a regular basis

Researcher: ok. And who was the first person I guess who noticed that you weren't well?

Participant: my GP

Researcher: yeah

Participant: yeah

Researcher: and that was around...?

Participant: well my husband said I was crazy all along but (laughs) he was pretty crazy himself. How long?

Researcher: mmh

Participant: after I first- I had been going to see him because of the problems in the marriage

Researcher: yeah

Participant: and the violence and that. And... I didn't know then but he had assumed certain things at that time. That I had depression and anxiety and everything. Um... what was your original question?

Researcher: no I was just saying, what year was that?

Participant: oh that would have been 96

Researcher: oh 96

Participant: it all started mid 96

Researcher: yeah

Participant: well the very first thing I noticed come to think of it... was a massive headache

Researcher: ok

Participant: yeah... and um... [Country N] for a holiday with my husband and kids and while I was over there I got this massive headache and it lasted and lasted for days and um when I come home I couldn't get out of bed um because of this awful headache. And um ...and it all started from that point on

Researcher: mmh...

Participant: that was about April, late April... the headache

Researcher: yep

Participant: I was crook in May... by the end of June I was not real well at all

Researcher: so when did you end up in [B Hospital]?

Participant: I can't quite remember but it was that year, later on... for that afternoon... and then I don't think I had much of an admission until 97

Researcher: ok

Participant : everything had fallen apart in my marriage by then... my ex kicked me out the house when I come home from [B Hospital]... and said he didn't want me there... so I took that to heart. That was the end of everything then. ah

Researcher: that was the end of 96? That was that year?

Participant: no 97

Researcher: ok

Participant: yeah

Researcher: and the first person you talked to was you GP?

Participant: yeah ok

Researcher: why did you choose you GP?

Participant: oh we chose that GP back in 1982 when we first got back from [City P].
We'd been in Perth for 18 months

Researcher: yep

Participant: and we come back over here and he- we first went to Dr [P] and then we ended up seeing Dr [L]

Researcher: ok

Participant: that who we saw at times- I was seeing him pretty much until he retired being a GP.

Researcher: mmh... ok... and um you know what was the role that health professionals played in your seeking help for your mental illness?

Participant: well I didn't really seek help. I didn't believe that there was anything wrong with me

Researcher: mmh huh...

Participant: um... but my first- other than that first trip to [B Hospital]. The first um contacts I had was through case- through the nurses. [Health Professional O] was the first person that I met

Researcher: oh yes

Participant: he used to come up on his motorbike. He eventually- he got me out of my home. He took me away from there

Researcher: ok

Participant: my ex used to threaten to call the mental health team not as a good thing- not as something to help me but as a threat. And um I remember [Health Professional O] was saying- we were driving away from there and he said: "at least I got you out of there"

Researcher: mmh...

Participant: and I remember one day... I was so distraught with the voices- I used to get this- it wasn't just what I heard but what I could feel...

Researcher: mmh...

Participant: physically. I felt like I've been tortured and had people operating my brain and I could feel it all. And it was very very painful and um [Health

Professional J] who was a mental health nurse at the time. She come round and gave me a Valium needle... to calm me down. It's all a bit of a blur after that. But then that was over a period of months. And that was the first psychosis that I had and then I went on to have other psychoses over the years

Researcher: yeah... and so what's the role that health professionals play in terms of you seeking help right now?

Participant: well ah took me out of a violent situation... um... I I felt like I had someone to talk to after all that period of years cause I never told anyone about what was going on at home... until then

Researcher: yeah

Participant: um... but I didn't want my marriage to end... I still wanted to work things out... yeah... I would have been stuffed without the mental health services though...

Researcher: yeah

Participant: I don't know what would have happened

Researcher: what kind of services did you receive?

Participant: um... well I had some time in [B Hospital], some time at the base hospital,

Researcher: yeah

Participant: I've had well over 20 trips to [B Hospital]... more close to 25, 30 now over a period of time. And um Dr [B] when I had some health insurance...

Researcher: mmh huh...

Participant: she sent me to [Clinic N] for 5 weeks

Researcher: yes

Participant: and that really helped a lot... that was 1998

Researcher: ok

Participant: aah... I met someone down there cause [my husband] and I were already-were separated by then. I met someone down there at the hospital and we had a relationship for about or 5 or 6 months or something. Um... and over a period of time I had [Health Professional Z] as my case manager

Researcher: yes

Participant: and he was very good. And also other ones. There was a lot of different case managers over the years. Can't remember all their names now (laughs)... [Health Professional F]... [Health Professional G]... a lot of different ones

Researcher: ok. What about now? What the role-

Participant: well [Health Professional K] just keeps an eye on me

Researcher: mmh huh

Participant: and gives me somewhere to ring. [Facility D] gives me somewhere to ring... if I'm not feeling well...

Researcher: mmh huh...

Participant: um... or if I'm feeling too well... when I get manic... then [Health Professional K] will notice that I'm not quite right... he keeps in contact with me... [Health Professional K]

Researcher: mmh huh

Participant: yeah. He's really good

Researcher: ok

Participant: yeah

Researcher: do you find that helpful?

Participant: yeah... I do... I just find that it gives me a sense of security... um...um... it's a shame that it's not 7 days a week

Researcher: mmh...

Participant: cause it used to be

Researcher: ok

Participant: when ah... I first got ill... you know like weekends and that and you if you weren't well and you rang the line they would turn up on the weekends and that as well...

Researcher: oh... alright

Participant: it was very helpful. But now it's just 9 to 5

Researcher: yeah

Participant: it's not even 9 to 5 it's 10 to 4

Researcher: and um what's the role that other people have played in your journey of seeking help for your mental illness? So other people who aren't health professionals...

Participant: well my daughter has been my best and greatest help.

Researcher: ok

Participant: um... she was only bout 16 when I first became ill. But she really helped me a lot and still does.

Researcher: what her name?

Participant: [M Girl] It's got to the point now where she doesn't want to be so involved because she's not feeling all that well herself um... so now I've been left alone a lot now which is a bit difficult um... other people... I've had friends over the years that have helped. a friend here and there... seems to have always been someone there I could ring. But a lot of it's been on my own... it's been a pretty lonely 15 years, 20 years now... 96... nearly 20 years... it's been quite difficult

Researcher: so does anyone- like you mentioned your daughter, what has her role been in influencing you to use mental health services?

Participant: well she just encourages me to get help

Researcher: yep

Participant: um... it's very hard for anyone to convince me to get help when I'm not well cause when you're that unwell you don't think you're unwell

Researcher: mmh...

Participant: so it's not that I was actually seeking it out when I wasn't well. It would come to me. And ah...

Researcher: so like you said you haven't actually sought help

Participant: well I have and I haven't. I have in between my psychoses... once it became apparent that I wasn't well then I would seek out the help a lot. Ah.. when I- back in 1998, 97 98, I sought services out a lot. I was probably ringing [Facility D] nearly every day

Researcher: ok

Participant: because I was so distraught... and didn't understand what was happening to myself

Researcher: yeah sure

Participant: and um... so yeah I was a probably a bit of a nuisance then for one stage... I just didn't know, I didn't know how to stand on my own two feet at all. Cause I'd gotten married at 17 so I was used to having that person in my life...

Researcher: mmh...

Participant : that I thought I could rely on so when that went I just felt so alone and uh I used to ring [Facility D] a lot... and had a lot of help

Researcher: does anyone influence your decision to use mental health services?

Participant: '[M Girl]' encourages me to talk to mental health services... um... she's really the only one

Researcher: yeah... you mentioned your partner before... how involved is he?

Participant: not involved at all

Researcher: ok

Participant: he doesn't believe in- that I'm even ill even when I'm not well he doesn't believe it

Researcher: ok

Participant: he's got a thing against psychiatrists

Researcher: ok... so he doesn't believe that you have a mental illness?

Participant: he doesn't believe in mental illness

Researcher: oh ok

Participant: he doesn't believe that there is an illness even though he did go through something similar in himself years ago

Researcher: ok

Participant: he was hallucinating himself and that and he talks about that but at the same time he doesn't believe...

Researcher: in mental illness?

Participant: yeah... it's frustrating really

Researcher: ok. but no one from what you've said, no one really influences your decision to use mental health services

Participant: well the mental health services themselves influence my decision

Researcher: ok

Participant: because they keep in contact and um... they make the appointments with the psychiatrists and I always stick to my appointments and so really it's coming from the other way round really

Researcher: ok. If we use the last month as a guide, can you think of um as many people as you can that you've had any sort of contact with... over the last month

Participant: [the] club house

Researcher: [the] club house

Participant: um my friend [Mr M], my daughter, [Mr R]- part time partner, um my friend [Miss D] down at [the clubhouse], um... I got a friend [Miss HM] who's been keeping in contact, I got a couple other people that I've talking to other than that. They're just friends

Researcher: mmh... it doesn't necessarily have to friends just people you've had an sort of contact with in the last month

Participant: mmh... all the people down at [the clubhouse]... ah... just various friends... [Health Professional K] from mental health, [Miss H] from mental health, um... went to the ladies group the other day for a little while

Researcher: ok

Participant: that's basically it really

Researcher: ok

Participant: well life's very much the same every day

Researcher: yep

Participant: which is a bit annoying. I mean I know I've gotta be the one to change it but I don't have the confidence to be out there and make my life better

Researcher: mmh... of those people that you've named, maybe there may be some others. Think of the people who made you feel good

Participant: um... [Mr M] my friend, [M girl] when we're not- we did have a couple of blues there a while back. That hurt me a lot. But once I got over that it was good again. My son [N boy], come round one day, I talk to him occasionally on the phone. Um... [Mr R]... I enjoy his company... mostly... (laughs)

Researcher: (laughs)

Participant: um... [Health Professional K's] really good. [Health Professional H's] good too.

Researcher: ok... um... anyone make you feel bad? Out of the contacts that you had?

Participant: my kids can be quite cruel sometimes

Researcher: do you only just have the 2?

Participant: I've got 3

Researcher: [M Girl], [N Boy] and [J Boy]. Where's [J Boy]?

Participant: he's in the [N State]

Researcher: oh ok. Wow he's far

Participant: yeah he is far away. But they can be pretty harsh sometimes and not very sympathetic. Um... so that hurts me because I love them very much.

Researcher: mmh... so who are the people who play an important part in your life?

Participant: my children more than anyone. [Mr R]... and [Health Professional K]...and [the clubhouse]... and my friend [Mr M]... he's great...we talk every day... that was him on the phone just then before

Researcher: so who provides you I guess with the most support?

Participant: my daughter

Researcher: yeah. Ok. So how often do you talk to your family and your friends or other people?

Participant: um... I talk to my daughter every day

Researcher: mmh huh... on the phone?

Participant: yeah and my friend in [N City] every day... nearly every day. My friend [Miss D] quite often and [Miss HM] quite often um... I ring other people too and they ring me occasionally... it's not a great deal of people really. And I don't do Facebook or anything like that. I haven't got a computer so I haven't got that sort of contact with anybody.

Researcher: ok. What means do you use though to communicate?

Participant: telephone... yeah I'm on the phone a lot... I'd be lost without my phone... and I also like talk back radio

Researcher: oh ok

Participant: yeah I get on the radio quite often at night that's what I was doing last night. I was listening to the radio and I rang them up

Researcher: oh ok

Participant: I got quite a rapport with a couple of the announcers on the radio

Researcher: oh that's good

Participant: mmh... it is good

Researcher: so you use mostly the phone?

Participant: yeah

Researcher: ok. But you spoke about [the clubhouse] so that'd be face to face?

Participant: yeah it is face to face. I go down there about 3 times a week

Researcher: ok

Participant: 3, 4 times a week.

Researcher: how do you find your time at [the clubhouse]?

Participant: aah... not too bad... it's become a bit boring lately and it's partly their internal problems that are causing that I think. It doesn't seem to be the things down there to do that there used to be... and um...

Researcher: so if you were in trouble, is there someone in your life that you can turn to?

Participant: if I was in real trouble my daughter would help me out... I have my family in [Country N] too... if I really was in big trouble um I could talk to them

Researcher: yeah. And ah, how can you tell that the people in your like really care about you?

Participant: well I know my kids love me even though sometimes it gets difficult. And the couple- 2 or 3 close friends, I know they care but yeah it's pretty lonely. Loneliness is hard

Researcher: yeah I bet it is

Participant: but I've got quite used to it now. Don't expect too much anymore. My expectations are a lot lower than they used to be

Researcher: it still makes it hard though

Participant: it does

Researcher: how do you know that the people that you do have, that you've spoken about, how do you know that they'll be there for you if you need help?

Participant: mmh... you just know these things... you know... you know they keep contact with me it's not just me contacting them

Researcher: yeah

Participant: um... but I often do feel very isolated

Researcher: mmh... even though you do have those people?

Participant: yeah. Even though I do have those people they've all got their own lives. Um... I feel pretty vulnerable...

Researcher: ok...

Participant: since my marriage broke up and I lost that role... that mothering role

Researcher: yes...

Participant: and the kids grew up and... You know... it just hasn't...um... I haven't really engaged life since really...

Researcher: do you think it's a process of finding your feet again?

Participant: well it is...but you think I would've by now (laughs)

Researcher: (laughs) takes us a lifetime to figure out these things

Participant: it does... it does... it really does

Researcher: so what support do your family and friends provide you?

Participant: aah... just more company... um... I got- my kids always say "I love you mum" at the end of every phone conversation and all that...

Researcher: do you see [J Boy] who's in the [N State]?

Participant: not much... and there's a rift there between us sort of... not that there's a dislike or anything... we like each other but um... when I got crook he seemed to pull away... and it's never been the same since.

Researcher: ok

Participant: yeah... and his wife didn't like me for a long time. We get along better now but for a long time she just didn't want anything to do with me so I've had very little to do with their kids

Researcher: ok

Participant: that was very heart breaking when they first had kids

Researcher: mmh...

Participant: I've got used to it now, not being involved

Researcher: is he the oldest?

Participant: mmh

Researcher: ok

Participant: I've got used to not being involved with their kids and that now but for a long time it really hurt me badly.

Researcher: mmh...

Participant: but I ended up gambling and that... I had a long affair with the poker machine over the years because of the heartache

Researcher: yeah... how many kids do they have?

Participant: they've all got 2 each

Researcher: how many kids does [M Girl] have?

Participant: [M Girl] has 2, [N Boy] has 2, [J Boy] has 2

Researcher: oh ok. So you're a grandmother

Participant: yeah

Researcher: ok. Do you see your grandkids?

Participant: not enough no. I see my daughter's kids a lot but the other 4 I don't see much of.

Researcher: ok. Is your daughter married?

Participant: yeah... well not married

Researcher: has a partner?

Participant: mmh...

Researcher: ok. Do you enjoy being a grandmother?

Participant: yeah when I get the chance to be one

Researcher: but you see your daughter's kids though.

Participant: yes

Researcher: do they come and visit you or do you go and visit them?

Participant: both

Researcher: maybe that's something I guess you could do more of

Participant: well... hopefully...

Researcher: do you feel like there is some you can trust with your worries and most private thoughts?

Participant: not really

Researcher: no...

Participant: only my friend [Mr M] I can talk to him about anything

Researcher: that's good that you have him

Participant: yeah... he's a great friend. Been friends since I started to go to [the clubhouse]. That was back in 98

Researcher: ok. So it's been a long time. You've been going there for a while

Participant: mmh huh...

Researcher: do you find the people at [the clubhouse] supportive?

Participant: yeah they are good. Mostly they are. Occasionally they come around here. Different people from [the clubhouse] come around here and visit

Researcher: anything else you'd like to add? Do you think we've covered it all?

Participant: I think we've basically covered it. Um... like I say it would be much more helpful if it was a 7 day a week service and also in [B Hospital] when you're a patient there and you wanna make a phonecall, you've gotta go through such a process... so frustrating and frightening cause you feel you can't walk out and you can't ring out... you feel like you're in a jail.

Researcher: thank you for talking with me today

ANNEXURE J: LETTER FROM INDEPENDENT CODER

RESEARCH DATA ANALYSIS REPORT

FOR: SOPHIA-LORRAINE NOXOLO ALLIE

DATE: 10 March 2016

STUDY: The role of social networks and social support on mental health service utilisation by mental health consumers in rural New South Wales.

INDEPENDENT CODER: Annatjie van der Wath

Method: Liamputtong's (2013:245) eight- step method summarised from Bryman (2012) was used to code the data:

1. Coding should be commenced while the data is being collected to enable the researcher to have a better understanding of the data.
2. The initial transcripts, field notes or documents should be read without making any notes or attempting to interpret the data. After reading the data a few notes can be made regarding what appears important or significant.
3. The data should now be read again but this time the researcher should make marginal notes about significant observations or categories that emerge. The researcher may use key words expressed by the participants or give names to themes in the data (this is coding).
4. The researcher generates an index of terms that will assist with the interpretation of the data.
5. The codes should be reviewed and if there are two or more words or phrases relating to the same issue, one of them should be deleted.
6. The researcher should consider theoretical notions as it relates to codes and data and to outline connections between concepts and categories that are being generated. The researcher should also think about how these concepts relate to the existing literature.

7. The researcher should not be concerned about developing too many codes in the early stages of data analysis.
8. A piece of data may be coded in different ways so the researcher should look closely at the data to see if it can be coded differently.

Saturation of data was achieved related to the major themes – The researcher conducted 12 interviews

Qualitative Data Analysis

This serves to confirm that Annatjie van der Wath has co-coded the following qualitative data: 12 interviews for the study:

The role of social networks and social support on mental health service utilisation by mental health consumers in rural New South Wales.
--

I declare that the candidate and I have reached consensus on the major themes and sub/ categories as reflected in the findings during a consensus discussion.

Annatjie van der Wath (M Cur, Ph D) annavdw@mweb.co.za

ANNEXURE K: EXCERPT FROM REFLECTIVE JOURNAL

Reflections 20 June 19 2015

I'm about 3/4 of the way through data collection. I'm starting to get really tired. It's been difficult trying to balance the demands of work and the research project. It has also caused me to think really deeply. I have been surprised how many of the participants have been willing to share their experiences with me. It seems like some of them have been waiting for this opportunity to share their experiences with me. I thought that the participants might find it difficult to speak to me because I am a health professional. Going into the research study I was keenly aware of the power imbalance that exists just because I'm a mental health clinician and they are mental health consumers. I have found that meeting the participants in their own homes has really helped this power imbalance. I have also endeavoured to treat each participant as an expert because that's what they are! I think my biggest surprise has been with regards to medication. As a health professional I assumed that the participants would indicate they hate being on medication but this hasn't been my finding thus far. Most of the participants have really positive things to say about medication. I am enjoying learning and being challenged by the data.