Barriers to the early identification and intervention of early psychosis among young rural males

Rhonda Lynne Wilson BNSc (JCU)

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I certify that the substance of this thesis has not already been submitted for any degree and is not currently being submitted for any other degree or qualification.

I certify that any help received in preparing this thesis, and all sources used, have been acknowledged in this thesis.

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Rhonda Lynne Wilson

Abstract

The literature shows that a lengthy duration of untreated psychosis has been recognised amongst young rural males. Early psychosis has been described as a cluster of symptoms marked by: hallucinations and delusions; thought disorder; and cognitive impairment and it is more prevalent amongst young males than young females. A significant discrepancy of duration of the length of untreated psychosis has been identified between rural and urban communities. This discrepancy has far reaching consequences for young rural men at a significant transitional developmental phase in their lives.

This study, conducted in rural communities in northern New South Wales, sought to understand the lived experiences of young rural males and their families in regard to emergent mental health problems, in an effort to recognise the barriers to earlier identification of early psychosis, and its timely treatment.

A qualitative research study was conducted which utilised an interpretive phenomenological analytical framework. Seventeen in-depth interviews were conducted following a media and snowballing recruitment strategy. Data analysis was conducted utilising thematic analysis. The major finding of this research was the identification of the early help seeking patterns of both the young men with emergent mental health problems and their families. A seven stage process was described whereby families are identified as possessing established skills as helpers. These skills are amendable for inclusion in the collaborative care planning for young men in rural communities.

Rural nurses are well positioned in the clinical spectrum to identify emergent mental health problems in the rural settings and to engage with young rural men usefully. They are rural community assets who have dual roles of nurse and resident community member in rural communities which provide them with a platform to enable early identification and intervention of young rural men and their families with emergent mental health problems.

This research contributes to the nursing and mental health literature, and has identified specific factors which influence the duration of untreated psychosis amongst young rural males. It has provided insight into the social discomforts and the unpredictable course of emergent mental health problems plus it has exposed the burden that is faced by parents who struggle to find help for their sons. Finally, it has highlighted the limitations which exist within rural health systems to adequately communicate mental health promotion messages to rural families and communities, and the failure to sufficiently invite young rural men to engage in early interventions treatment.

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I would like to dedicate this work to my children. I remain their biggest fan.

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Definitions

The following list of definitions is provided to assist with conveying the meaning of key terms in this thesis.

Rural

Rural is a term that is ambiguous in common usage. Rural is defined by government organisations according to the measures of the Accessibility Remote Index of Australia (ARIA) and/or the Rural Remote and Metropolitan Areas (RRMA) index (Department of Health and Ageing 2009). Northern inland NSW is largely classified as a rural zone according to these measures. However, the researcher notes that in the context of the data collected for this research, rural is whatever the participant says it is. Participants in this study are more likely to consider themselves as *country* people rather than rural people by virtue of their residence in, and connection to northern NSW. While rural is a term that has some specific definitions, in the context of this thesis it is used as a broad term to denote people who live in communities outside of urban jurisdictions.

Early psychosis

A collection of signs and symptoms which are usually characterised by disordered thinking, and/or presence of delusions and /or hallucinations (EPPIC 1998).

Duration of untreated psychosis

Duration of untreated psychosis is the period between emergence of psychosis and the time at which clinical intervention commences to treat psychosis.

Comorbidity

The existence of more than one disorder simultaneously which adversely effects health

	and/or wellbeing. In the context of this thesis, comorbidity is often noted as the dual problems of psychosis and drug use, particularly cannabis use. However, other comorbid conditions are noted in the literature review chapter of this thesis. Comorbidity is sometimes referred to as dual diagnosis. The terms are used interchangeably in the literature.
Prodrome	This term denotes the period of time which precedes the clinical threshold phase of acute psychosis. Prodrome is most obvious in retrospect and is often described as a 'not quite right' phase. This phase is also difficult to distinguish between normal adolescent developmental phases. Thus, prodrome is especially difficult to determine during the prodromal phase (EPPIC 1998).
Young men	Young men are considered to be young within the context of this thesis between the ages of 18-25 years of age.

Chapter One

Introduction

1. Introduction

Early psychosis affects some young men in rural communities in northern New South Wales so the timely detection and early intervention of early psychosis among this group is of clinical importance. However, a significant discrepancy of duration of untreated psychosis has been identified between rural and urban communities (Catts 2007; Hoolahan 2002). This discrepancy has far reaching consequences for young rural men at a significant transitional developmental phase in their lives. Therefore, understanding the reasons why young men in rural communities have a longer duration of untreated illness is of particular relevance, and this research study has focussed on this specific problem.

The researcher is a mental health nurse clinician, with many years experience, who has recently led a regional project to address the early psychosis needs of young people in northern inland New South Wales. Anecdotally, and during the course of the regular work associated with this project, the researcher noted a higher than anticipated incidence of early psychosis, and that the advanced ages of first episode of psychosis clients in the region reflected a probable lengthy duration of untreated psychosis (Wilson 2008). As a result, this study sought to understand the lived experience of young rural males and their families in regard to emergent mental health problems, in an effort to recognise the barriers to earlier identification of early psychosis, and its timely treatment. It reports on the lived experiences of thirteen participants from rural communities in northern New South Wales, and their journeys of helping or being helped during the emergent phase of mental health problems in their lives.

1.1 Background to the study

The onset of early psychosis usually occurs between the ages of 12-25 years and it is significantly more prevalent amongst males (EPPIC 1998; Edwards & McGorry

2002; ORYGEN Youth Health 2004; Amminger et al. 2006). The signs and symptoms of early psychosis can vary widely, however they are usually evidenced by disordered thinking, and/or the presence of delusions and/or hallucinations (EPPIC 1998). A prodromal phase, or pre clinical threshold phase, can be identified most usually retrospectively (EPPIC 1998). The transition of this prodromal phase to acute phase is often murky and frequently this process is described by observers as a *'typical troubled teenage'* phase. Distinguishing between emerging early psychosis and normal adolescent developmental phases is especially difficult (ORYGEN Youth Health 2004).

According to several authors (EPPIC 1998; Edwards & McGorry 2002; ORYGEN Youth Health 2004; Amminger et al. 2006), best prognoses are associated with earlier interventions. Early psychosis responds well to treatment interventions. However, the duration of untreated psychosis commonly is a period of six months to two years, with a longer duration of untreated psychosis more likely among rural populations (Amminger et al. 2006; Boyd et al. 2006; Endacott et al. 2006; Judd et al. 2006; Aisbett et al. 2007).

Contextually, the condition of psychosis and the dynamics of rural service delivery models and intervention pathways are further reported in the literature (Alexander & Fraser 2008; Bambling et al 2007; Boyd et al 2008). The stoic nature of rural people, together with stigma, and close social proximity despite geographical distance are factors which are implicated in the discussion of barriers to early identification and intervention of early psychosis in rural communities (Aisbett et al. 2007).

1.1.1 Timeliness of the study

This study was conducted at a time when health services and Governments across Australia were exploring opportunities to improve the delivery of mental health services to young people (Hodges et al. 2007). In recent times, federal funding has been designated specifically to this problem (McGorry et al. 2007), and in remote parts of Australia, federally driven programs have been initiated and maintained (Northern Territory Government of Australia 2007). State based youth mental health services have been recognised as falling a long way short of the mark (McGorry et al.

2007). Letters to editors in health journals and popular press have stimulated discussion and new debates have broken out amongst health care professionals and politicians about the suitability of these radical programs (Byrne & Blackett 2007; Coffin 2007; Jones 2007; McGrath 2007).

Therefore, it would appear that youth mental health issues have a social and political timeliness at present, with an articulated 'hope' for an improved future for this group. It is particularly timely to investigate youth mental health issues in more detail, specifically it is important to consider if the present and proposed models of service delivery are the most appropriate models, and to include a consideration of the specific dynamics required to develop suitable service delivery models for rural young men who live in rural communities (Boyd et al. 2007). It will be crucial to look though the veneer of rhetoric around 'best ways forward' notions. The findings of this study will make important contributions to mental health service model developments specifically designed to help young rural men early in their morbidity profile.

1.2 Aims

The major aim of this study was to gain insight and understanding into the experience of the young men and their families by asking: *What is the lived experience of young rural men with emergent mental health problems such as psychosis?* In exploring the experience of the young men and their families in this study, the researcher sought to address the following specific research questions.

> *What are the barriers that prevent young rural men and their families from accessing appropriate help early?*
>
> *Do young rural men and or their families know what to do when something is not quite right and when early mental health problems start to emerge?*
>
> *What is it like to try and find appropriate help in rural areas?*
>
> *How do young rural men and their families select help and where do they seek help?*

When rural young men and families ask for help, do they receive suitable/useful help?

This study sought to discover the barriers to early participation in mental health treatment experienced by young rural males and their families.

1.2.1 Significance of the study

The findings of this research make a clinical and theoretical contribution to mental health nursing. The findings are also significant in regard to policy development, especially for planning resources to match client population needs to actual mental health service delivery outcomes. An early help seeking model has been suggested which can be applied to early intervention service delivery models, and this will assist in closing the gap between help seeking and mental health service delivery. This contribution is aimed at reducing the duration of untreated psychosis amongst young rural males. This research has identified the patterns which families and young men use prior to accessing formal mental health services. It is important information to have this phase identified because it makes it clear to policy makers how mental health services can work towards meeting clients earlier on their help seeking trajectories. It is likely that the burden of morbidity will decrease in acuity as mental health services are able to position accessibility opportunities closer to the emergent phase of mental health disorder.

The clinical significance of this research is that it highlights some characteristics of the lived experiences of young rural men and their families during the emergent phase of mental health problems. This research interprets the decision-making and behaviours of young rural men and their families and communicates this information to clinicians. This information is especially useful when applied to the early mental health assessment of young rural men and their families and in the management of their mental health care. The most important reason for this research is that, the lengthy duration of untreated psychosis experienced by young rural males, adversely affects their long term prognosis and associated recovery periods. The discovery of the barriers to early identification of early psychosis amongst young rural men will

help to achieve a reduction in the length of untreated psychosis, thereby feasibly improving prognoses for this group.

A social significance can be ascribed to this study because it has provided insight into the social discomforts and the unpredictable course of emergent mental health problems and it has exposed the burden that is faced by parents who struggle to find help for their sons. Public mental health awareness and literacy in rural populations is acting to reduce the stigma associated with mental health problems. As these populations become more aware of the characteristics of emergent mental health problems and the struggles encountered by families, it may be possible to nurture greater social capital within rural communities to better support vulnerable community residents.

1.3 Methodology

A qualitative study was conducted which utilised an interpretive phenomenological analytical framework. Seventeen in-depth interviews were conducted following a media and snowballing recruitment strategy. Data were collected as digital voice recordings which were transcribed and coded. Thematic analysis was undertaken by conducting focused paper based coding and line-by-line software assisted coding utilising nVivo8. The following emerging themes were identified.

Theme 1: Help-seeking.

Sub theme 1: Reluctance to identify as having a mental health problem.

Sub theme 2: Vocabulary barriers.

Theme 2: Unpredictability and social discomforts.

Sub theme 3: Geographical issues of social stigma and social proximity.

Sub theme 4: Emergent symptoms of psychosis and depression.

Theme 3: Parents struggle to find help for their sons.

Sub theme 5: How long is a piece of string?

Sub theme 6: Parental roles and concerns.

Sub theme 7: Parental emotional burden.

The major finding of this research is the identification of the early help seeking patterns of both the young men with emergent mental health problems and their families. The researcher devised a seven stage process to describe the early helping seeking activities of young rural men and their families. Families have well established skills as helpers. These skills are amendable for inclusion in the collaborative care planning for young men in rural communities.

This study has identified a problematic public health mental health service admission classification system which currently is in use and which is underpinned by traditional medical modelling. On the occasions that the young men and or their families in this study did seek help outside the family, they were required to negotiate complex admission to service criteria which do not always reflect the human experience of emergent mental health problems. In particular, the gate-keeper roles of reception activities in public health and private practice settings are problematic.

The clinical implications of the findings are that rural nurses are well positioned in the clinical spectrum to identify emergent mental health problems in the rural settings and to engage with young rural men usefully to treat emergent mental health problems. Nurses have a discipline-based knowledge matched suitably to commence appropriate family-based interventions which usefully address the cluster of emergent mental health problems experienced by young rural men. Rural nurses are rural community assets who have dual roles of nurse and resident community member in rural communities which usefully provide them with a platform to enable early identification and intervention of young rural men and their families with emergent mental health problems (Boyd et al 2008; Endacott 2006).

1.3.1 Limitations and key assumptions

This study was conducted within the geographical region of northern New South Wales. It describes the lived experience of thirteen participants who at the time of this study, resided in northern New South Wales. The findings are not intended to

represent the wider population or other geographical settings as only specifically, young rural men and their parents participated in this study. All participants volunteered and self-identified as meeting the inclusion criteria for this study following either a public invitational media release or as a result of snowballing recruitment.

It needs to be noted that the pool of potential informants for this study may have naturally occurring limitations in regard to their capacity to have sufficient insight in regard to emergent mental health disorders and/or reduced functional cognitive capacity, but this was not tested. All participants had a relevant life experience that they could meaningfully relay during in-depth interviewing which revealed an emergent mental health problem for a young rural man. The data in all cases contained rich human experiences which described the phenomenon under investigation.

1.3.2 Organisation of thesis

This thesis is presented in five chapters. The following summarises the content of the remaining four chapters.

Chapter two reviews the literature about early psychosis issues and especially as it relates to young rural males. In particular, literature about co-morbidity and dual diagnosis; rural dynamics and service delivery models; and intervention pathways are explored.

Chapter three describes the methodological approach utilised in this study. A qualitative interpretive phenomenological analytical framework was chosen because it retained the capacity to address the research topic through the in-depth exploration of human lived experience.

Chapter four explores the data and provides an interpretation of the data. The themes which emerge from the data analysis are presented and discussed. Chapter five presents the major findings, conclusions and recommendations which arise from the study.

1.4 Summary

This chapter has introduced the importance of understanding the issues that underpin the barriers to the early identification and the appropriate and timely treatment of emergent psychosis amongst young rural men. It has described the background context for a study of this type, and has highlighted the importance of findings which can contribute to the national discussion about youth mental health service models. The methodology for this study was introduced and an overview of the key findings was presented. The significance of the study was discussed, and limitations and key assumptions have been described.

The next chapter of this thesis will review the literature about early psychosis and its relationship to young rural men.

Chapter Two

Literature review

2.1 Introduction

This chapter will review the recent literature and other professional discourse in relation to early psychosis, comorbidity problems, the dynamics of rural lifestyle and accessing appropriate help-seeking and early treatment pathways. It has a particular emphasis on young rural men and it commences with an overview of early intervention in mental health in Australia. Definitions of early psychosis, its timely detection and rationale for early intervention will be clarified, exploring both an Australian and international perspective. Four sections have been used to present this discussion to assist with dealing with the breadth of literature that was reviewed and which forms the basis for this researcher's enquiry.

Section One introduces some key terms and background context. Section Two outlines issues around comorbidity and particularly the complications of drug use in the context of early psychosis. Section Three explores rural dynamics and service delivery models that impact on young rural men and families. Finally, Section Four identifies appropriate treatment pathways and interventions for young men with early psychosis.

2.2 Section One: Key terms and background context.

This research is particularly concerned with rural young men and their emergent psychosis. Rural will be considered from a lived experience vantage point, that is, how rural people see themselves. The term 'rural' is used differently in various rural communities. In the NSW region where the sample for this study was drawn, rural people refer to themselves as *country people* and, in contrast, rural people in northwest Victoria refer to themselves as *desert people*, people in western rural NSW communities between Broken Hill and Bourke refer to themselves as *outback* people, and south west Queenslanders refer to themselves as people *in the bush.* It is

interesting to note that rural people have a variety of terms to describe their personal connection with their rural place of residence.

These same places are arbitrarily categorised by systems such as government departments, academic and business sectors as *rural, remote and very remote* (Department of Health & Aging 2009). In describing where people live for systematic governance, economic power or distribution of services perspectives, we lose some of the richness in meaning of what it means to live as a *country* person or to live *in the bush*. The sense of being a *country* person rather that a *rural* dweller has further intricacies in the local vernacular. People may use terms like *old mate* to describe another person whether they are an actual mate or not. The labelling infers an inherent sense of connection, support and interrelatedness, which is part of rural lifestyle. It is the lived experience of rural young men and their families which is the focus of this research. Understanding the richness that is attributed to this experience provides some context for understanding the experience of emergent psychosis in this setting.

Psychosis is a general term used to describe a cluster of symptoms marked by: hallucinations and delusions, thought disorder, and cognitive impairment. Often these symptoms are also accompanied by mood disorders, loss of insight, excitement or aggression and anxiety (EPPIC 1998; American Psychiatric Association 2000). The onset of early psychosis usually occurs between the ages of 12-25 years. It is significantly more prevalent amongst males (EPPIC 1998; Edwards & McGorry 2002; ORYGEN Youth Health 2004; Amminger, et al. 2006). A prodromal phase, or pre clinical threshold phase, can be identified most usually retrospectively (EPPIC 1998). The transition of this prodromal phase to acute phase is often murky. Frequently this process is described by observers as a *typical troubled teenage* phase. Distinguishing between emerging early psychosis and normal adolescent developmental phases is especially difficult (ORYGEN Youth Health 2004).

2.2.1 Detection and duration of untreated early psychosis

Early psychosis responds well to treatment interventions (EPPIC 1998; Edwards & McGorry 2002; ORYGEN Youth Health 2004; Amminger, et al. 2006). The best prognoses are associated with earlier interventions. However, commonly the duration of untreated psychosis is a period of six months to two years, with a longer duration of untreated psychosis more likely among rural populations (Amminger et al. 2006; Boyd et al. 2006; Endacott et al. 2006; Judd et al. 2006; Aisbett et al. 2007).

The timely detection and early intervention of early psychosis among young rural males is of clinical importance. Understanding the reasons why young men in rural communities have a longer duration of untreated illness is of particular relevance. A significant discrepancy between urban and rural populations, with a sizeable disadvantage amongst rural dwellers is noteworthy. An examination of the dynamics of residing in rural communities together with the lived experience of young rural men and their families with emergent early psychosis problems will provide insights into why such lengthy duration of untreated psychosis exists for this population. The literature clearly highlights that anything that can be done to reduce the duration of untreated psychosis will be especially beneficial in regard to reduced morbidity and reduced severity. This research study seeks to explore this issue.

2.2.2 Lengthy duration of untreated psychosis for young rural men

The literature does not suggest specific reasons for a delay in identifying early psychosis amongst young rural males. Commonly, there is a six month to two year delay in the identification of early psychosis and in initiating appropriate treatment for this disorder (ORYGEN Youth Health 2004). Some researchers indicate that a duration in untreated psychosis may even occur for up to ten years in rural Australia (Catts 2007). Further complications occur with longer delays for the early identification of mental health issues in rural communities, especially for young people (Boyd et al. 2006). More males than females are affected (ORYGEN Youth Health 2004). Together the issues combine to create a complex problem and give rise to the following questions:

- What are the barriers that young men experience in getting help early?
- What delays the early identification of early psychosis?
- What are the experiences of young men in rural communities in relation to these issues?

If mental health and other community service providers had the answers to questions such as these, they could then feasibly plan to remove these barriers and thereby enhance the access opportunities for young rural men into appropriate early intervention services. Health service planners and providers would be usefully informed by gaining a richer understanding of rural young men's cultural and sense of 'place' issues. These concepts, once understood, should be integrated into early psychosis treatment practices within rural settings. Further, it is vital in terms of prevention and early intervention that the findings of research which answers the above questions, informs the health promotion agenda such that the identified needs of young men in rural communities are reasonably met.

However, the most important reason for exploring these questions is that, the lengthy duration of untreated psychosis experienced by young rural men, adversely affects their long term prognosis and associated recovery periods. Discovering the barriers to early identification of early psychosis amongst young rural men will help to achieve a reduction in the length of untreated psychosis, thereby feasibly improving prognoses for this group.

2.3 Section Two: Co-morbidity and dual diagnosis

According to Carey et al. (2007), *co-morbidity* and *dual diagnosis* are terms used throughout the literature to describe a situation where a client presents with both mental illness and drug and/or alcohol abuse. These terms are sometimes used interchangeably and inconsistently. On occasion, dual diagnosis may be used to describe both mental illness and developmental disability, while co-morbidity might also be used to describe mental illness in conjunction with other disease processes, for example diabetes (Baptista 2004; Ross 2006). Both terms have been used in the literature to describe mental illness and drug and/or alcohol relatedness. While the use of these terms can be confusing, and can complicate the review of literature, it

does, however, demonstrate the complexity related to attempting to isolate individual clinical determinants. In reality, very often mental illness does not exist in a vacuum, and often co-exists with other disorders of various types and intensities. Therefore, it is useful in the context of exploring the barriers to identification of early psychosis among young rural males, to consider the coexisting circumstances which may have an impact on emerging mental illness.

2.3.1 Comorbidity and drug relatedness

It is inconceivable to consider exploring issues around early psychosis without also acknowledging the impact that drugs have on the experience of psychosis (Degenhardt & Hall 2001; Lynskey et al. 2003; Degenhardt et al. 2007). However, there remains a lack of an empirical causal linkage in either direction. There is no evidence to suggest that drug use/abuse causes psychosis or that psychosis causes drug use. What is evident is that there seems to be a relationship, and that both conditions seem to co-occur for some individuals (Degenhardt & Hall 2001; Fergusson et al. 2002; Australian Institute of Health & Welfare 2005; Ferdinand et al. 2005; Fergerson et al. 2005; Dubertet et al. 2006; Degenhardt et al. 2007). While it is difficult to ascertain specific prevalence of both psychosis and substance use, conservatively around 50% of clients with psychotic disorders experience substance use disorders in their life time was found by Gregg et al. (2007) in a meta analysis of which is discussed further in the literature.

The following four explanations have been proposed which deal with comorbidity related to substance use and psychosis: 1*. Substance use causes psychosis; 2. Substance use is a consequence of psychosis; 3. Both substance use and psychosis have a common origin; 4. Psychosis and substance use interact to maintain each other* (Mueser et al. 1998; Gregg et al. 2007).

2.3.2 Cannabis use causes psychosis

A number of empirical studies have concluded that there is a link between drug use and psychotic symptoms, although none have suggested what the causal factors

were (Ferdinand et al. 2005; Green et al. 2005; Raphael et al. 2005; Wade et al. 2005; Hall 2006). Hall (2006) conducted an epidemiological review of large-scale longitudinal studies of young adults in developed societies over a 20 year period. His review identified evidence which suggests that young adults who commenced consuming cannabis in their early to mid adolescence had an increased risk of using other illicit drugs, educational underachievement and experiencing symptoms of psychosis (Hall 2006). Hall (2006) specifically reports that while cannabis appears to have a contributory effect, it is not clear if a causal effect can yet be identified. D'Souza et al. (2004) conducted an experimental investigation and found that delta-9-tetrahydrocannabinol, the psychoactive component of cannabis, can produce transient psychosis-like symptoms in healthy individuals. However there was no evidence to suggest that cannabis use causes long term psychotic illness.

2.3.3 Stress causes psychosis

Another model that has been suggested is the stress-vulnerability model whereby a person copes with a steady mental state by balancing his/her inherent personal stressors and vulnerabilities until such time as a trigger interrupts the balance and instigates a psychotic response (Zubin & Spring 1977). Hambrecht and Hafner (1996) conducted a retrospective study of 232 consumers diagnosed with schizophrenia and found that two thirds of the sample used drugs prior to developing schizophrenia, one third commenced using drugs around the time of diagnosis of schizophrenia. They interpreted these findings in terms of the stress-vulnerability model (Zubin & Spring 1977), and considered that factors such as reduced coping resources as a result of drug use, cumulative vulnerability, and self-medicating to cope with the symptoms of schizophrenia, were likely to explain comorbidity (Hambrecht & Hafner 1996). Hambrecht and Hafner (1996) reported that stress was the underlying vulnerability, and that once this threshold was breached, schizophrenia resulted. Stress may be either *a* factor, or *the* factor in triggering psychosis in vulnerable individuals (Zubin & Spring 1977; Phillips et al. 2007). Stressors are frequently related to childhood trauma such as: sexual abuse; physical abuse; and/or trauma. These types of incidences have a relationship to psychosis

and are considered risk factors, if not causal factors (Bak et al. 2005; Read et al. 2005)

2.3.4 Cannabis use does *not* cause psychosis

There is plenty of evidence to suggest that cannabis and perhaps other drugs alone *do not* cause psychosis (Dubertet et al. 2006). Australia has a high prevalence of cannabis use, yet not everyone that uses cannabis acquires psychosis (Australian Institute of Health and Welfare 2005; Mental Health Council of Australia 2006). Almost half of the population of Australian adolescents have a life time experience of cannabis use (Australian Institute of Health and Welfare 2005). If indeed cannabis (drugs) cause psychosis, then we would expect to see a vastly higher demand on mental health services in Australia, however this is not the case (Degenhardt & Hall 2001; Lynskey et al. 2003; Degenhardt et al. 2007). Therefore it can be concluded that cannabis does *not* cause psychosis in *all* individuals. But, whether it is a causal factor in some individuals continues to perplex researchers.

2.3.5 Amphetamine use results in hospital admissions with psychosis

A new trend is emerging in Australia where an increase in amphetamine related hospitalisations for psychotic episodes has been documented. The Australian Institute of Health and Welfare manage a National Hospital Morbidity Database which is a collection of data from all state and territory health authorities. Hospital separations can be extracted from this data set. Hospital separations describe the reason for admission to a health service based on treatment received at the conclusion of the hospital stay (Degenhardt et al. 2007). Degenhardt et al. (2007) conducted a systematic review of hospital separations across Australia between 1993 and 2004, and they discovered a relationship between methamphetamine use and psychosis, which resulted in involuntary hospital in-patient admission. Further, these clients were also likely to have aggressive behaviours which were more pronounced than that of those clients using cannabis and experiencing psychosis.

The author found that the risk of hospitalisation for amphetamine related psychotic episodes is greater than cannabis related psychotic episodes (Degenhardt et al. 2007).

2.3.6 Mental illness causes substance abuse

Yet another model suggests that substance abuse may be the result of mental illness, that people with mental illness struggle with the discomforts of positive symptoms (usually described as the delusional symptoms), negative symptoms (usually described as the more depressive symptoms) and uncomfortable medication/treatment side effects (Mason & Beavon-Pearson 2005; Gregg et al. 2007). These circumstances predispose such people to drug and/or alcohol use and/or abuse, and, these people are likely to 'self-medicate' with drugs to abate the discomforts that they experience (Khantzian 1985; Khantzian 1997). Gregg et al. (2007) suggest that there is a natural bent towards this idea because it has an intuitive appeal. Further, people with troublesome positive symptoms may be more likely to self-medicate with cannabis and other drugs, whereas, those with more burdensome negative symptoms are more inclined towards alcohol (Dubertret et al. 2006; Talamo et al. 2006).

2.3.7 Self medicating with drugs to ameliorate symptoms of psychosis

Regardless of causal explanations around 'which came first', the mental illness or the drug use, there are further descriptive studies throughout the literature around the concept of 'self-medicating' with drugs to counter the symptoms of psychosis with these drugs (Carey 2007; Mason & Beavan-Pearson 2005). Of note is the age at which exposure to drugs occur, the earlier the onset of drug exposure the greater the disposition to psychosis, however this does not increase the likelihood of continued drug use and therefore does not support the self medicating notion (Henquet et al. 2006). Better pre-morbid cognitive functioning often predicts more successful recovery in relation to psychosis (ORYGEN Youth Health 2004). However, sustained

drug use is believed to cause cognitive decline (Mental Health Council of Australia 2006).

2.3.8 Social functioning

Typically, drug-using first episode of psychosis clients are most likely to be male, young (adolescent), with poor cognitive and/or academic functioning, who have regular contact with a large group of friends pre-morbidly (Larsen et al. 2006). This profile is interesting because while this population of young males may struggle at school, they are reasonably socially successful, and perhaps this continues throughout the emergent phase of psychosis. This stronger social drive (which is a key ingredient in the procurement of drugs) has been recognised previously, but has not been the subject of research in its own right. Rather, it seems that this aspect has been illuminated in the course of answering other research questions (Dubertret et al. 2006; Talamo et al. 2006). Most studies have not separated out the social and cognitive functioning aspects, but have treated them as a single variable, and as a result, most studies have found a relationship between drug use, poor cognitive functioning and psychosis. According to Larsen et al. (2006) identification of a strength in social successfulness may be a useful future line of enquiry for researchers to pursue.

Interestingly some researchers have found that individuals who have used drugs, especially cannabis, prior to their first episode of psychosis have higher cognitive outcomes and represent a higher functioning sub group (McCleery et al. 2006), than people who have not used drugs previously. This sub group has also been defined as having better social successfulness, higher parental socio-economic circumstances and fewer negative symptoms, while drug naive first episode psychosis clients may be more likely to experience more negative symptoms (Carey et al. 2003). In some ways this is resonant with common sense in that it takes a high degree of social successfulness and cognitive functioning and planning skill to maintain and sustain drug use behaviours. Intuitively, it is plausible that first episode of psychosis clients with a history of drug use will have a higher pre-morbid cognitive functioning capacity.

2.3.9 Post morbid drug use cessation

It is clear from the literature and the researcher's experience that the cessation of drug use following the emergence of psychosis is important for a good recovery prognosis (Larsen et al. 2006). Miller & Rollnick (2002) have compared the effectiveness of motivational therapies with a range of other therapeutic interventions and found that the use of motivational strategies were appropriate ways to both develop insight and motivate change amongst drug using populations (Miller & Rollnick 2002; Stephens et al. 2004; Miller et al. 2005). Motivational therapies form the basis of best practice care management for substance withdrawal and cessation of use behaviours in client populations and can be applied in the context of dual diagnosis early psychosis (Miller & Rollnick 2002).

2.3.10 Drug use and psychosis share a common origin

It is possible that psychosis and drug use share a common origin, due to either biological, social or individual factors (Gregg et al. 2007). Genetic factors may be responsible for vulnerability to both drug use and psychosis, although this remains poorly understood. Cognitive deficits are common to both morbidity profiles. For example, recent clinical neurophysiological research from Germany has highlighted similarities between the endogenous cannabinoid system and the endophenotypes of schizophrenia, a marker system identifying cognitive measures of functional capacity (Solowij & Michie 2007). It is thought that a population-wide vulnerability exists for a psychosis phenotype, whose expression can be triggered by cannabis use (Solowij & Michie 2007). It is conceivable that a dysfunction in the endogenous cannibinoid system may lead to higher rates of cannabis use and a subsequent risk of psychosis (Van Os, Henquet et al. 2005; Van Os, Krabbendam et al. 2005; Henquet et al. 2006).

Psychosis and drug use may also find a common origin in social and environmental factors, such as childhood trauma, abuse or other disadvantages. Lynskey and Hall (2000) reviewed cross-sectional and longitudinal evidence from Australian and other developed countries, and reported that adolescent uptake of cannabis use predicted poor educational attainment, delinquent behaviours and affiliations, and mental

health problems. They further suggest that amotivation perpetuates and magnifies the problems of continued drug use and mental health decline (Lynskey & Hall 2000).

Cougnard et al. (2007) conducted a prospective study using the data from two large longitudinal random populations' studies in the Netherlands and Germany. They found that environmental factors accumulated additively and that this occurred synergistically with an underlying population-wide proneness to low-grade transitory psychotic experiences. Additive accumulation of environmental factors, such as drug use, combined with psychosis proneness, may contribute to a persistence of psychotic symptoms, which may be indicative of a poor prognosis (Cougnard et al. 2007). Thus, it is plausible that common origins for both drug use and psychosis exist, and that when a threshold is reached the expression of both problems are exacerbated.

2.3.11 Psychosis and drug use: maintaining the balance

Finally, a maintenance model has been suggested. Gregg et al. (2007) have reviewed the maintenance balance and they describe the notion of both psychotic and drug use disorders interacting with each other in such a way as to maintain and sustain the other (Barrowclough et al. 2007). People with psychosis and simultaneously drug use dependency, struggle with similar issues in relation to limited coping strategies, low self efficacy, difficulty with managing stress, and negative symptoms such as depression (Gregg et al. 2007). From a social learning theoretical perspective, people in these circumstances often utilise a maladaptive routine of coping, and may foster a belief system which reinforces their maladaptive coping, for example the positive effects of drugs (Bandura 1977; Abrams & Niaura 1987).

2.3.12 Summary.

There is no clear way to comprehensively understand the linkages between drug use and psychosis because there are a number of perspectives to take into account. It is

not yet possible to fully substantiate a causal link in any direction; however there are some strong indications that psychosis and drugs do interact, and that their combined profiles complicate both disorders significantly. This study explored the lived experiences of young rural men in regard to emerging psychosis and drug usage.

2.3.13 Birth order and psychosis

An interesting aspect to consider may be that birth order plays a part in predisposition in regard to psychosis. Gaughran et al. (2007) conducted a comparative analysis study in the United States of America which explored schizophrenia disorders among 150 sibling pairs. They discovered that later born children have a poorer recovery prognosis and an earlier onset of symptoms then their older siblings. They proposed that an explanation for this may lie in an incompatibility of the maternal-foetal genotype, and that the intrauterine environment might deteriorate with subsequent pregnancies (Gaughran et al. 2007). Thus, a genetic or environmental factor may be implicit as a comorbid factor, which may assist in explaining the onset of psychosis in an individual later in life.

2.3.14 Genetics and psychosis

A range of disorders have been linked to a genetic syndrome 22q11.2 deletion syndrome, also known as Velocardiofacial Syndrome and DiGeorge Syndrome (Gothelf et al. 2007). This syndrome occurs as a result of a deletion within chromosome 22. Gothelf el al. (2007) conducted a cross sectional study and compared an affected group with a non affected group. They were able to determine that a high rate of psychotic disorders occured in conjunction with 22q11.2 deletion syndrome (Gothelf et al. 2005). Murphy et al. (1999) conducted a similar study with a similar design and found that a genetic vulnerability also existed whereby autism spectrum disorders, attention deficit hyperactivity disorder, and obsessive compulsive disorder were more likely to co-exist with psychosis than with a non affected group.

2.3.15 Metabolic disorders and psychosis

Metabolic syndrome is a comorbid condition which is increasingly recognised in conjunction with schizophrenia. In the recent literature in Australia there has been some discussion around whether it is a side effect of first and/or second generation antipsychotic medications (Usher et al. 2006). However, a distinct set of clinical indicators and known risk factors have been described in relation to the metabolic syndrome. The prevalence of metabolic syndrome is noted to be widely distributed within the population and is not limited to only people taking antipsychotic medication (Baptista et al. 2004; Healy 2005; Usher et al. 2006). Metabolic syndrome is defined by a cluster of obesity, hyperlipidaemia, type 2 diabetes, and diabetic ketoacidosis with obvious increased risk in regard to cardiac disease (Baptista et al. 2004). Lambert et al. (2003) conducted a meta analysis of research literature related to schizophrenia and comorbidity and found that people with schizophrenia have a reduced life expectancy, and, that there may be a relationship between this and morbidity related to metabolic syndrome and cardiac disease. It will be important for a young person who is in the early phase of the psychosis–schizophrenia spectrum that consideration is given to planning for the prevention of the development of metabolic syndrome as a recognisable potential risk factor.

2.3.16 Mood and behavioural problems complicate psychosis recovery

One survey study in the United States of America found that 99% of a sample of 81 four to fifteen year olds who were diagnosed with childhood-onset schizophrenia had a comorbid diagnosis of attention deficit hyperactivity disorder, oppositional defiant disorder, or depression or separation anxiety disorder (Ross et al. 2006). These are alarming rates of comorbid presentations of young clients, and demonstrate that the earlier the onset of psychosis, the poorer the prognosis is likely to be. These types of conditions in combination represent a major challenge to the treatment of and recovery from psychosis in the Australian context (ORYGEN Youth Health 2004).

2.3.17 Visual and neurological factors related to psychosis risk

According to Schubert et al. (2005), visual dysfunction in early childhood may indicate disturbed neurological development, especially in children of psychosis affected mothers. Disturbed neurological development is also a characteristic of psychosis evolution. Visual dysfunction may affect cognitive and perceptual development and these are also risk factors associated with the development of schizophrenia (Schubert et al. 2005). Schubert et al. (2005) conducted a prospective study, using a standardised assessment instrument of vision at four years of age, and, neurological status at six years of age. An interview was conducted to assess for psychological problems at 22 years of age. This study found that visual deficits recognised at four years of age were selectively predictive of psychosis at 22 years of age and that neurological deficits were also related to visual impairment. Predictive assessment instruments applied in early childhood could shed light on risk for psychosis during young adulthood, especially when emergent psychosis is difficult to diagnose in its early phase. This type of assessment could contribute an important component in enabling early identification of early psychosis for young rural men, however, it may not be practical on a population screening scale.

2.4 Section Three: Rural dynamics and service delivery models

This section will present a discussion of the way in which rural dynamics interact or are mismatched with service delivery models in rural communities and consider the impacts of these factors. Rural dynamics and service delivery models emerged as a theme in the literature.

2.4.1 Models of mental health service delivery to rural populations

At the time of this study, it appears that youth mental health issues have a social and political timeliness, with an articulated ‘hope’ for an improved future for this group. Therefore, it is particularly timely to comprehensively investigate youth mental health issues. It is important to establish if the present and proposed models of service delivery are the most appropriate models for addressing the mental health needs of

young rural people, and to include an overview of the specific dynamics which need to be considered in developing suitable service delivery models for rural young men, living in rural communities (Boyd et al. 2008). It will be crucial to peer though the veneer of rhetoric around the 'best ways forward' notions. One such current government funded offering is the national *headspace* youth service model (Hodges et al. 2007). *headspace* has as few as 29 centres operational throughout Australia, with 16 of these in urban and large regional locations. Only two *headspace* centres in rural settings are operational, and both are in South Australia (www.headspace.org.au 2009). Hodges et al. (2007:78) claimed that 'over the next 2.5 years, *headspace* centres will be established in cities, rural and remote locations across Australia.' At the time of this study, only 3 months remain whereby it could be anticipated that *headspace* will achieve its goals. It seems unlikely that rural communities can expect a great deal more from this national initiative to address youth mental health. Rural young peoples' capacity to gain access to this current service stream is significantly limited when the number of communities across Australia is taken into account.

The federal government in Australia has endorsed and funded national *headspace* initiative. To date however, this initiative fails to sufficiently articulate how it will fit with the local and embedded grass roots capacity of local rural communities. Rather, the *headspace* model represents a dichotomy in that it seeks to send in the 'knights in shining amour' bearing gifts of training, systems, integration and coordination instead of utilising the already embedded systems and skilled workforce that pre-exists in these communities. A potential conflict of interest is endorsed whereby it's invited 'stakeholder groups' of select for-profit private practitioners such as, primarily medical practitioners and psychologists, will gain financially from its exclusive system (Hodges et al. 2007). The strategy fails to recognise that rural communities have unique networks and expertise embedded within them which are assets to harness from a grass roots perspective, and that integration and coordination capacity already exists in the microcosm of rural communities (Boyd et al. 2008). This is demonstrated by the way in which rural nurses, in particular, engage within their communities, and the dual relationships that they manage as both community member and nurse (Endacott et al. 2006; Boyd et al. 2008).

Thus, there is a sense that *headspace* may replicate what already exists in rural communities, and fail to strengthen the assets already inherent in the communities. It would seem that the hype of the latest fashion in youth mental health, *headspace*, is likely to fall on the same sword as many other programs have in the past. *headspace* has been required to develop a sustainable funding model for ensuring accessible youth mental health services to young people in rural communities (Hodges 2007). However, *headspace* have not been able to demonstrate within their current cycle of initial funding, how they will be able to achieve this. The reality appears to be that *headspace* have been unable to implement the program adequately for rural young people.

This comes as no surprise to many commentators who have been advocating for some time that rural communities contain strong community assets which could be better utilized if funding was made available to support local initiatives (Boyd 2008; Mathie & Cunningham 2003; Varpalotai 2005). For example, Varpalorai (2005) describes a school and community healthcare partnership which was formed in one rural Canadian community. The experience gained as a result of that youth service model implementation, may inform Australian service planning because there are many similarities between the two countries in regard to population, rural settings and health services. A model that has been successful in a Canadian rural setting has nurtured a 'web of support' which was developed from a grass roots level and it utilises the core assets of the community such as accommodating the local workforce to develop services which best fit the needs in the local community. This innovative model had local appeal and it captured the strengths contained within the community and used them effectively. Government funding was made available for this initiative, following recognition that prior government imposed programs which relied on 'sending in' services and workers failed to meet the needs of the local rural community (Varpalotai 2005).

Mathie and Cunningham (2003) have suggested an alternative to the traditional needs-based approaches to community development. The Asset-based Community Development (ABCD) Model suggests that once local skills are identified within a community these skills, often previously unrecognized or supported, are in fact a community asset which when harnessed usefully provide local citizens with a framework to build social capital. Boyd et al. (2008:5) suggests that this 'bottom-up'

approach is more useful than a 'top-down' approach to community development and they endorse this approach especially when applied to the mental health of rural men. However, mental health programs in rural communities which have been underpinned by this type of modeling have not attracted renewed funding to continue their programs despite achieving clearly successful outcomes (Morell et al. 2006; Prabhu & Browne 2007).

Prevention and early interventions in regard to early psychosis and emerging mental illness do not always require the discipline expertise of psychiatrists and clinical psychologists. Despite this, both medicine and psychology feature predominantly in the *headspace* model (McGorry et al. 2007). It is vital that pathways are established for young people to commence a help-seeking journey as the needs emerge (Boyd et al. 2008) and they may begin that journey with the internet (Burns, Morey et al. 2007), or through immediately accessible networks and services (Morrell et al. 2006; Varpalotai 2005). Pathways for mental health help-seeking are many and varied, and not restricted to specific disciplines and organisations. Not all help seekers will need highly specialised interventions. Therefore, it seems paradoxical to develop a 'soft' entry point in *headspace,* which is underpinned with 'hard' medical and psychological clinical interventions.

According to Wilson et al. (2005) the key factors for young people commencing help seeking are that they often choose someone that they know, for example their parents and friends, and they require an established and trusted relationship with these people. Family doctors, youth workers and school counselors are likely to act as 'gate keepers' to mental health services for young people (Wilson et al. 2005; Alexander & Fraser, 2008). Thus the literature supports the notion that young people who are early mental health help seekers are likely to be seeking help from helpers who are not likely to be medical doctors or psychologists. However, the literature also indicates that government funded public service providers are geared towards providing medical and psychological models of service. Thus, the service providers and the help seekers may not be attuned to each other. A threat to successful help seeking and appropriate service provision is identified where the two parties are polarized and not recognised by each other in a meaningful way. The literature illustrates a significant gap in this regard, that service providers attempt to deliver a service without a model to capture early-entry help seekers. Conversely, the help

seekers are looking for help, but not from the service providers who are seeking to offer help. This communication hump represents a barrier which has received scant attention in the literature, or in service plans. The narrowness of models which are funded to provide services limits the effectiveness of mental health prevention, promotion and early intervention aspirations.

Furthermore, researchers and psychiatrists in Australia currently recognize that the medical model which underpins the current youth mental health model has a number of weaknesses, and that if the medical profession has a goal to diagnose, treat and predict outcome, then a more meaningful model which accommodates the vagaries of emergent mental illness needs to be developed (McGorry et al. 2007). This would require systemic changes of inclusion criteria for treatment and a reluctance to diagnose according to traditional methods. A staging model is proposed which retains a significant 'diagnose, treat, and predict outcome' medical focus which aims to accommodate earlier identification and earlier treatment potential (McGorry et al. 2007). A limitation of this model is that it has a purely diagnostic/medical focus and fails to explore a more diverse range of modeling opportunities such as nursing models, which may in collaboration with other disciplines such as medicine, present an eclectic opportunity to better address the shortfalls in youth mental health service provision (Cashin 2007).

2.4.2 Summary

It is evident from the literature that services for young people with mental health problems are not aligned from a range of perspectives. The help-givers sought by young people are not usually mental health professionals. Young rural people are further removed from helping connections by the structures imposed on rural communities to utilise 'outsiders' who do not have local social and trust capital within the community. To further complicate matters the funded models, such as *headspace* (Hodges et al. 2007; McGorry et al 2007), used to underpin helping for young people does not articulate with the practical lived experiences of the early phases of emergent mental health problems. While models such as the Asset-based Community Development initiatives (Mathie & Cunningham 2003) have greater

articulation with the emergent mental health problems of young people, they are not publically funded and therefore not readily available to rural young people.

2.5 Section Four: Intervention pathways

The activities associated with helping young rural men with emergent mental health problems and their families are also discussed in the literature. The interventions, or the activities of helping are sometimes matched well to the client population, but a number of gaps are also evident. The following section reviews some current intervention and helping pathways that are utilised in Australia.

2.5.1 General practitioners: An unconfident 'catch-all' approach

Collins and Holmshaw (2008), two United Kingdom based researchers, surveyed 130 teachers from three secondary schools for males and females in the UK about their knowledge regarding early detection of early psychosis. Their findings paint a similar picture to the Australian context in that, teachers are able to detect emerging mental health problems which, in general, they thought might be psychosis or schizophrenia (Boyd et al 2006). The findings of the UK study showed that the teachers were unable to agree on suitable pathways to commence help-seeking. Interestingly, they thought that family interventions might be a suitable solution, but did not identify a pathway from problem identification to intervention implementation. The findings also showed that the teachers were most likely to refer to a general practitioner (GP), or a psychiatrist, indicating that they did not have a knowledge of the various treatment pathways that might be suitable (Collins & Holmshaw 2008).

This preference to refer to a GP as a 'catch-all' for all problems may be problematic if indeed GPs are not the most suitable source of appropriate help during emergent phases of psychosis. The traditional role of the GP to *do everything* and *fix all health problems* is increasingly problematic. Alexander et al. (2008) conducted a survey in rural GPs in New South Wales which found that they are not confident in helping young people with psychosis. Therefore, GPs and/or the public health system may not be best positioned and prepared to be an entry point for the help seeking activities of young men and their families with emergent mental health problems. In

the UK and Canada, both countries with significant similarities to the Australian culture, have similar difficulties in establishing a pathway for early mental health help for young people. There is a common recognition that the longer these illnesses are left untreated the worse the prognosis is likely to be (Johannessen 2001; McGorry 2004; Collins & Holmshaw 2008). Yet, internationally a significant problem remains in identifying an early pathway to source appropriate help for emergent psychosis.

2.5.2 Inner strength and support

Gorman et al. (2007) conducted a qualitative study which utilised indepth interviews to explore the experiences of rural men and their coping strategies with mental illness. Their sample consisted of ten rural men living in Queensland who were older than 18 years of age, and who could identify with feelings of extreme emotional difficulty, depression and thoughts of suicide. The two main themes were identified which assisted in forming resilience and coping: *individual and inner strength; and support and strategies.* Their study found that if coping with mental illness is underpinned by an established sense of inner strength and with adequate support, then it would seem that building these protective characteristics within rural communities should be entirely possible. The resulting population-wide resilience is likely to have a positive impact on the burden of mental health problems within the rural community. Nurses and other health and education professionals, together with families are likely to play an important role in fostering these characteristics.

Conversely, inner strength resources and maintenance of support systems for young rural men are diminished when emergent mental health problems arise and behavioural oddity commences. On the one hand there is a hopefulness that inner strength and support will protect, but on the other hand young prodromal men may not be able to access these resources.

Additionally, rural men are noted for their stoicism, and their lack of recognition of triggers for mental health problems such as relationship breakdown. They are likely not to consider that depression is a mental health problem, rather it is just the way things go, or simply part of life on the land or in the rural economy, with drought and other agri-problems (Gorman et al. 2007). Boyd and Parr (2008) reviewed the

literature which described the social geography of rural people and noted that rural people share a social proximity even though they are more geographically distant to their urban counterparts. A close social proximity is an important aspect of rural culture and identity. A threat to this important rural dynamic is that social exclusion is a cost that often accompanies mental illness (Boyd & Parr 2008). Judd et al. (2006) conducted a cross sectional community survey of 467 rural residents in New South Wales. Rural men who were identified as stoic were less likely to undertake active mental health help-seeking. However, when mental health problems start to impact on successfulness within the social structure of the rural community, and social exclusion or stigma starts to develop, it comes at a significant personal cost (Judd et al. 2006; Boyd & Parr 2008).

2.5.3 The role of the rural nurse

Frequently rural nursing takes on a specialist-generalist role based on necessity. Broader eclectic nursing skills are required in the bush, rather than fewer skills and a narrower range of expertise that often accompanies specialist urban nursing (Hegney 1996). Rural specialist-generalist nursing has a recognised function in rural settings and has an especially useful function when applied to early psychosis in rural settings (Edwards & McGorry 2002; Wilson 2007). Nurse practitioner models are developing slowly in response to the need for improved youth mental health service delivery. Funding bodies continue to prefer the traditional gatekeeper-style medical organisations to administer, manage and supervise the work of specialist-generalist nurses. This traditional model of service delivery acts to perpetuate health service delivery adherence to medical models and does not accommodate the flexibility required to deliver health services outside of this restrictive paradigm. Medical models do utilise nurses within general medical practice settings as general practice nurses in general medicine. Specialist-generalist nurses or nurse practitioners in rural settings can offer a complementary health service which is matched to the client need and is either inter or independent in delivery, but which contrasts markedly with the more apologetic role of the medically managed general practice nurse (Cashin 2007). Specialist-generalist nurses are nurses who have developed specialist skills across a broad range health issues. They operate in generalist settings, however

their expertise in assessment and nursing management is evident at an advanced level of practice. They are specialist at generalist practice (Wilson 2007).

Rural nurses have a range of local dual roles and relationships which position them uniquely in relation to the early identification of emergent mental illness. They are in a position to notice change and to engage in informal discussions about the early identification and early intervention of young rural men, as a result of their embeddedness within community and their legitimate community membership. They are assets within their communities in this regard. There is a credible argument which suggests that specialist-generalist nurses in rural communities add an element of community protection and community health promotion as a resident community member, thus adding an asset which can't be replicated by visiting services or by rural people attending out-of-town specialist appointments in larger referral centres (Boyd et al. 2008).

Nurses are the most abundant population of health workers in rural areas of Australia (Rajkumar & Hoolahan 2004), so, it is important to consider how this resource might be utilised most effectively to address the needs of young rural men with emergent mental health problems. These authors also indicate in their literature review that nurses, especially generalist-specialist nurses, are well placed to assess and to intervene early in rural and remote communities (Rajkumar & Hoolahan 2004). Generalist-specialist nurses are nurses who have developed expert knowledge and practice in generalist nursing. Operationally this level of skill by nurses is recognised as specialisation in general nursing (Edwards & McGorry 2002; Wilson 2007). This has the added benefit of reducing the duration of untreated psychosis for young rural men. Rajkumar and Hoolahan (2007) suggest that further research should be conducted to explain why the clinical work of such nurses and its proven efficacy is not implemented on a widespread basis. Currently, state health systems and national medicare provider rebate models of health service delivery in rural Australia do not adequately support nurses taking a more assertive role in managing this health problem phenomena more actively.

2.5.4 Young people and trust

Rickwood et al. (2007) published a review which explored what is known about how and when young people seek professional help for mental health problems. Their synthesis of the review reveals that young people are more likely to seek help for emerging mental health problems with people they already have a trusted relationship with, for example their parents feature as a first port-of-call. Following parents as first help choices, are trusted teachers, school counsellors, sports coaches, and general medical practitioners as likely entry points for help seeking (Rickwood et al. 2007).

Some indentified barriers to help seeking for young people include a history of a previous negative experience with someone the young person had identified as a helper, and the poor mental health literacy among potential helper's at an initial point of seeking-help (Rickwood et al. 2007). This is of particular interest because it would seem that many of the first choice of trusted helpers identified by the young men may well be part of a base line of the Australian population which have a poor general knowledge of mental health problems (Logan & King 2001; Zachrisson et al. 2006). Adolescent males are recognised as having a poor general knowledge about mental health problems and low mental health literacy (Rickwood et al. 2004).

Young people are also concerned with privacy, confidentially and social proximately within rural communities. This is a recognised barrier to seeking mental health help (Aisbett et al. 2007). The stigma associated with mental illness continues to be a significant barrier for young people in rural areas, especially when these people have concerns about confidentially. Nurses and health professionals have a variety of community roles, one of which is as mental health professional. The community role/s of this person is a dynamic which needs to be considered in light of social connectedness to the client or the clients extended family (Boyd et al 2008; Aisbett et al. 2007).

If a threat to trust is perceived by the potential client, then difficulties surrounding access to help arise. Furthermore, the physical distance between rural communities can be a deterrent to help seeking, combined with a lack of choice in regard to specialist workforce individuals who are locally available (Wilson 2007).

2.5.5 Adolescent & young adult transition

Late adolescence and early adulthood requires the negotiation of significant developmental milestones. In particular, this is a period of transition, and often vocational training or preparation, which results in establishing vocational and relational success (Killackey et al. 2006). Young adults strive to achieve milestones of gaining financial security, independence, acquiring resources such as cars and stable accommodation, undertaking and completing training and acquiring employment, as well as finding and forming life partnership relationships. These are important developmental aspects which occur in a relatively short time period in human development. Delays and interruptions are not easily regained in this life stage, especially in regard to vocation and training, and may result in young people being out of step with their peers (Killackey et al. 2006). The previously highlighted lengthy duration of untreated psychosis experienced by young rural men is a major disparity for this group compared to their urban counterparts, and may adversely impact the later years of their life considerably given the strategic importance of successful and timely negotiation of young adult developmental stages.

The stress-vulnerability model described earlier in this chapter informs the risk and risk reduction spectrum which can be applied to the transitional nodes which young people negotiate (Zublin & Spring, 1977). Nodal points, such as a young person's transition from school to workforce, represent a vulnerable phase but also a known opportunity for early recognition of emergent mental health problems (Killackey et al. 2006). Limiting the disruption to developmental phases of young people, and identifying emergent mental health problems early is likely to improve wellbeing on a number of health and social fronts.

2.5.6 Motivational therapies in early intervention

Motivational interviewing is a well known and efficacious intervention, particularly for people with drug and alcohol morbidity (Miller & Rollnick 2002), and it is potentially useful for some comorbid psychosis affected clients (Miller et al. 2005). Some authors have recognised that it may require some modifications in therapist delivery

style and that it may not be suitable for all comorbid substance-psychosis clients (Martino 2007). However, it has been successfully adapted for some client profiles (Carey et al. 2007). Specifically, it can be noted that psychosis profiles vary among individual presentations, and many presentations will consist of significant generalised cognitive dysfunction, negative symptoms including amotivation and depression, and positive symptoms such as delusions, hallucinations, bizarre thinking and unusual beliefs. In contrast, substance use clients without comorbid psychotic disorders are more likely to present with life style related problems, greater cognitive flexibility and functioning and less severe negative symptoms.

The cognitive advantage that the substance use population exhibit is likely to be more amenable to motivational interviewing interventions (Carey et al. 2007; Martino 2007). It is timely to recall the aforementioned identification of social successfulness as a strength and predictor of better recovery prognosis amongst comorbid substance use and emergent psychosis profile whereby a consideration that higher premorbid functioning is indicated in this group, as opposed to the profile group of evolved psychosis and later substance use group, where poorer cognitive functioning was noted (Carey et al. 2003; McCleery et al. 2006). Thus, motivational interviewing may require some refinement for use with comorbid psychosis and substance use clients where premorbidly the client had a history of social successfulness, cognitive functionality and symptomatically fewer negative symptoms (Carey et al. 2007).

2.6 Conclusion

This chapter has reviewed the literature which describes three prominent themes relating to rural young men with emergent psychosis and their families. The complexity of comorbidity and dual diagnosis has been reviewed, as have the rural dynamics and service delivery issues. A range of intervention pathways, and helping activities have also been explored. The literature reviewed has informed the basis for this research study.

The next chapter of this thesis will address the methodology utilised to undertake this research study.

Chapter Three

Methodology

3.1 Introduction

This chapter describes the research design and the methodological approach used to investigate the research problem. It commences with a justification for the research design and methodology adopted in this study. The research setting, sample, data collection procedure, data analysis procedure and ethical considerations are described and discussed. The measures taken to ensure rigor and trustworthiness of the study are described and discussed. Finally, methodological limitations are identified and discussed.

3.2 Justification for the qualitative research design and methodology

This study utilised an interpretive phenomenological analytical framework which is proposed by Smith et al. (1995) and adapted from van Manen's (1990) earlier phenomenological methodology. For this study, the researcher wanted to explore the lived experiences of young rural men aged 18-24 years and their parents or significant others, about their personal experiences of the emergent mental health problems of themselves or their significant young man. In this way it was possible to investigate the barriers to accessing mental health intervention at an early phase of morbidity for this group. The researcher chose a qualitative design for this study because qualitative research methods are widely recognized in the literature as appropriate where the investigation seeks to explore the rich meaning of human experiences (van Manen 1990; Hallett 1995; Smith et al. 1995; Annells 1999).

The researcher was not interested in quantifying factors, measurement of variables, or in the cause and effect relationships of the phenomenon under investigation. However, the researcher was interested in understanding the experiential dynamics of early mental health problem morbidity and the journey that a family and/or young

man transits through enroute to achieving eventual intervention. The fluidity of this phase combined with the vague and insidious development of symptoms further implicate the use of interpretive phenomenological methods whereby participants are interviewed and re-interviewed at a later time to gain vertical depth in data and to develop a vertical and horizontal saturation in the data (Smith et al. 1995). The researcher rejected van Manen's (1990) phenomenological design primarily because it did not accommodate the re-interviewing and the capacity to capture a deeper saturation of data over time. Smith et al. (1995) research design methods facilitated the capture of data which met the requirements for this study, and was chosen on that basis.

A further illustration of the usefulness of this methodology being applied to the research question was identified during the data collection phase of the study. A young male participant with an emergent mental health problem was involved in a single vehicle motor vehicle accident and sustained a closed head injury in between interview one and interview two. The cascade of events and the questions it raised about the young man's mental health was especially informative in regard to establishing a sequence of events and tracking the problem solving which was applied to this sequence of events. This data was especially rich, and would have been missed if a single interview had been used as the sole data collection tool. A second interview gave rise to participant reflection on what had happened during the phase between interviews, and provided detailed information in regard to the complexity of confronting problems on a sequential basis.

Smith (1995) and Boyd (2008) suggest that this type of sequential interviewing yields a vertical depth in data sampling and enables the researcher to explore the research phenomenon with sufficient depth to usefully understand the life story which is under investigation. One incident in isolation would have been rich data in itself, but to see a number of crises develop over time for this participant and his family provided a saturation of experiences rather than an isolated event. The motor vehicle accident gave rise to questions about the young man's cognitive abilities, suicidal thinking and/or actions, and whether these may be changing over time.

Reinterviewing participants was validated by other findings drawn from the data also. On each occasion, the what-happened-next factor was instrumental in understanding

the lived experience of either having an emerging mental health problem as a young rural male, or as parent or family member helping a young rural male with emerging mental health problems. This methodology underpinned exploring the constant readiness that the families apply to their circumstances as a general underlying coping strategy for their young male person, and how the rapid changes that occur as life is lived by all, impact significantly on the help seeking behaviours of the family and the young male person.

3.3 Reflective Journal

Emergent psychosis is difficult to decipher from the sometimes less smooth developmental transitions that adolescents' negotiate as they transit to the end of adolescence through to young adulthood. The researcher's capacity to critically think through the clinical issues that were evident, while simultaneously conducting a research interview with a research participant was especially useful. This was particularly useful when issues arose which related to normal emotional ranges and connectedness, delays in perception, or unusual perceptions, disordered thinking and cognitive difficulties. Notably, thought disorder, cognitive compromise and, perceptual problems are all characteristic of early psychosis. Thus, it was important that the researcher was able to pick up on these characteristics as they developed within the context of an in-depth interview, with both the young men and their parents. It was useful to be able to enquire further about these issues, once they emerged in the course of the interviews. Thus, an important aspect of this study was that the researcher had explicit clinical mental health competence.

The researcher commenced a reflective journal prior to commencing sampling. The researcher has practised nursing in the areas of mental health and addiction in rural settings for many years, and she was aware that she came to the research topic with a wide range of clinical experiences. The researcher was aware that this experience would inform the research study, but it could also compromise the rigor of the study. The researcher decided to use a reflective journal as a tool to record her clinical impressions, if these ideas arose, and to bracket her experiences to further refine the sampling and analysis techniques. Walker (2007) argues that developing authenticity in the data requires that the researcher implement strategies to ensure that the

experiences of the participants are recorded faithfully and that this is indeed an ethical issue for a qualitative researcher to consider. This bracketing technique was used in this study and is well described in the literature. When applied, it assists the researcher to deal with the preconceived ideas and notions which may bias the collection of authentic data, in such a way that these ideas are firstly acknowledged by the researcher and notionally separated from the data (Merleau-Ponty 1964; Glaser & Strauss 1967; Husserl 1970; van Manen 1990; Smith et al. 1995).

The researcher recognised that a core component of her clinical practice experience had required her to develop skills in exploring clinical problems during the interviewing of clients. These are important clinical assessment techniques, and are critical in terms of delivering good mental health assessments and proposing suitable interventions. These skills on the one hand lend themselves to proficiency with conducting in-depth interviewing techniques of study participants, but on the other hand, represent a bias towards clinical impression forming rather than researching the nature of human lived experiences (Minichiello et al. 1995). The goal of this research was not to assess participants in the way a nurse might interview a client, but rather to create an opportunity for the participant to share their own experiences of their personal story around the research topic, and not to be subjected to formal clinical assessment. A reflective journal was used to optimise a rigorous approach to sampling, and as a tool to counter the possibility of exploring clinical style problems during participant interviews. Notes were recorded in the researcher's journal following each participant interview. Clinical impressions which the researcher developed were recorded in the reflective journal, and these ideas were then isolated in the journal and not included in the analytical process to the best of the researcher's ability. Recognition of this potential bias from the outset enabled the researcher to bracket for this potential threat to rigor. Van Manen (1990) makes it quite clear that it is almost impossible to achieve complete and objective bracketing of clinical impressions and the clinical knowledge by the researcher, when the researcher is both a researcher and an experienced clinician. Additional literature endorses this notion (Smith et al. 1995; Walker 2007), however the literature also indicates that rigor is gained and research design is strengthened by the acknowledgement of this potential weakness prior to sampling and analysis of data. The literature also indicates that the researcher should act to minimise any bias in an

effort to produce trustworthy and rigorous research findings (Burns & Grove 1999; Smith et al. 2006; Walker 2007). Thus, bracketing was conducted by the researcher to ensure rigor throughout the research process.

The reflective journal was a useful tool for recording a range of peripheral information which was not central to the research study, but which informed the context in which the research was conducted. For instance, communications with media outlets following pre-recorded and live-to-air media interactions used for recruitment were important aspects to reflect on. This study attracted public interest following radio and local newspaper coverage of the media release prepared for the media dissemination. Interestingly the people responding to this media were largely middle income, middle aged people. The reflective journal was a useful avenue to record this information initially, as all respondents to the media release were not selected for participation in the study. The reflective journal was used to record and consider this dynamic, which became increasingly meaningful following sampling and during the analysis phases of the study.

The reflective journal was also a useful tool to record details about the participant's interviews following the interview. In particular it was useful for refining the interviewing process for subsequent interviews and to further focus the interview processes. Further, mapping the field lay out for interviews was also instructive during the data analysis phase (Minichiello et al. 1995). These maps facilitated a recall of seating arrangements and visual eye contact opportunities, which added meaning and emphasis to specific verbal content on some occasions, for instance when a husband and wife made contact with each other during the interview process to validate their recall of chronological and emotional events using non verbal means of communication such as eye and body language.

3.4 Research Methods

The study methods included semi-structured in-depth interviews, utilizing a funneling technique (Smith et al. 1995). Participants were recruited from responses to a media release which was disseminated across print, voice and vision media and with further snowballing and purposive selection following the initial media recruitment phase.

The sampling method which was used required only a small number of participants, with participants re-interviewed following preliminary analysis of data to further develop depth within the study (Smith et al. 1995). Data was analyzed using a focused coding technique (Smith et al. 1995:40) which formed the basis of a thematic analysis and formulation of primary themes and sub themes, and the ensuing development of a model which may explain the phenomenon under investigation (van Manen 1990).

A pilot study was conducted and during the pilot in-depth interview it became evident that the methodology was well suited to the research enquiry. Use of an interpretative phenomenological analytic framework accommodated initial interviewing, analysis of the data and then the re-interviewing of participants. Participants were able to tell their story to date, and then time was able to pass sufficiently to accommodate the what-happened-next phase of the life story to unfold. This was demonstrated as one participant told of an incident which was at that time currently unfolding. For this participant, an impending family crisis was looming in relation to the behaviour of his son who was exhibiting signs of an emerging mental illness. The participant had trialled a number of strategies to deal with his son, and he was waiting to see if they would work. The outcome was unknown at the time of the first interview. The participant had a number of alternative strategies to apply if his first batch of strategies failed or did not produce the result he had hoped for. It was immediately obvious that the ongoing story would be relevant to the research findings. The researcher needed to gain a greater depth of understanding about how the participant formulated his ideas about developing his self-made interventions to treat his son, and the researcher also needed to understand if they would work, or if they would form part of a help seeking pathway, perhaps towards a formal mental health assessment. Thus the methodology which was chosen was validated during the sampling phase, reinforcing the concept of returning to the participant for a further in-depth interview to gain a deeper and more rigorous collection of data.

3.5 Setting

The settings where the interviews took place were determined by the participants. In general they were places where the participant felt sufficiently comfortable to tell his or her personal stories around a very sensitive topic. A vacant bed and breakfast accommodation business belonging to two participants made a very suitable interview environment for those two participants, as it had no interruptions or distractions. It was very private, and was perhaps better than conducting an interview in the participants' home, primarily because the discomfort of discussing sensitive personal issues could in a metaphorical sense be left behind. This gave the participants the opportunity to retreat to a private personal space at their home to recover from thinking about issues which had emotional costs associated with them. These matters were considered by the researcher as valid ethical obligations and contributed to success in gaining authentic data. Mental health issues are recognised as sensitive topics and perhaps more so in socially proximate rural settings (Walker 2007; Boyd et al. 2008), thus every attempt was made to ensure that procedures were built into the study's design to ethically obtain sensitive information and rich research data.

For a second interview, two participants were happy to be interviewed in their own home. Trust and rapport had developed over the course of the first interview, and the subsequent interview in their home offered a deeper level of sharing of personal information. Some skeletons-in-the-closet were more readily disclosed in this second interview, for example, extended family members with long standing mental health problems; and, traumatic family relationship breakdowns. This very private information which had it been disclosed in a first interview, may have not been discussed with sufficient candour due to potential concerns about trust establishment with the researcher and social stigma about mental illness within the extended family. Thus, interviewing participants on a second occasion did ensure for saturation of the topic under investigation.

Another setting used to conduct an interview was a coffee shop in the early morning. This was a good environment because it was busy and noisy which offered an emotionally safe space to talk about a topic which was heavily laden with emotional impact. The additional noise did impede the quality of voice recording, however to

counter this problem the researcher transcribed the interview recording within 24 hours of conducting the interview, and wrote memos in regard to the interview immediately following the interview. This enabled the collection of data and supported the participant who was especially keen to provide information for the study, and did not want to cloud her thinking with losing her composure and rendering her less able to be articulate as she wished. She wanted to express some difficulties she had encountered in accessing suitable help for her son. The cafe environment assisted her in maintaining sufficient emotional composure to verbalise her thoughts, such that she felt she had disclosed the information that she was willing to contribute to the study. The researcher demonstrated how she sought to meet ethical obligations towards the person participating in the study, while simultaneously ensuring the quality capture of valid data. Creating an opportunity for the participant to choose a setting for her interview helped to promote a sense of confidentiality for the participant which Walker (2007) describes as a useful process for validating congruency with research design selection. Burns and Grove (1993:578), advocate that participants should be interviewed in a relaxed atmosphere with ample time to allow for complete description by the participant. This was achieved within all the interviews of the participants for this study and this is further reflected in the choices of interviewing venues chosen by the participants.

The various choices of interviewing environments made by different participants were of interest. The recruitment strategy for this study attracted a number of reasonably affluent, middle income families. The interviewing environmental choices are perhaps where middle aged and middle income people feel most comfortable when discussing sensitive topics in rural communities. These settings contrast strongly with the types of mental health environments that these people might encounter, during a help seeking phase. It may be that the state health service environments are geared more towards low socioeconomic circumstances and in doing so may inadvertently repel middle aged, middle income circumstances. This is an area worth exploring further in another study.

'Having a coffee together' is conducive to conversation and people sharing personal stories. This aspect together with the physical environments assisted in creating a suitable milieu for the in-depth interviews to take place.

3.6 Sampling procedure

A media release was used to recruit the sample (Appendix 1) and a specialist journalist assisted in refining the media release tool. The researcher wrote an initial template for the media release. The journalist and researcher met on several occasions to further refine and rework the tool. A number of drafts were developed before a final draft was sent out to a wide range of media agencies within the northern New South Wales region, for example: to Australian Broadcasting Company (ABC) regional radio; local regional newspapers and local commercial television broadcasters. During the drafting process references to mental illness, mental health services, and clinical nursing were removed. It was important to refine the media release in such a way as to target as selectively as possible the group of people of interest for the research topic. Given the sensitivity of the topic, it was especially important to make sure that the media release contained plain language that would engage, rather than repel potential respondents. Therefore the researcher sought to remove any language references in the media release which might be a threat to recruitment. Utilising a skilled journalist to assist in this process was a strategic method used to recruit the sample.

This procedure was developed as a result of the researcher's previous experience in convening a rural conference addressing the topic of psychosis. On that occasion, a media release was issued with the assistance of a number of communication specialists. While the target group for the conference were rural clinicians working in the mental health field, interestingly the researcher received many telephone calls from rural parents of young people who had experienced mental health problems. While this response had been unintended on that occasion, it did indicate that a number of people are likely to respond to media around this sensitive topic for investigation and that they were willing to share their stories, or were keen to be heard on this topic. Gorman (2007) found that the use of media in a recent qualitative study of Queensland rural men's experience of suicidal thinking and depression, had a limited, but sufficient response rate with a similar sampling framework to the one conducted in this study. Burns and Grove (1993:255) further indicate that media support is a useful recruitment strategy for sampling. Thus, there were a number of good indications to suggest that a well constructed media release would invite an adequate response to participant recruitment.

A total of ten responses to the media recruitment and a further six responses via the snowballing technique were captured. Snowballing occurred by word-of-mouth where members of the public expressed an interest in the study and requested information to pass on to people whom they considered may be interested in the research topic because of some personal resonance within their personal experiences. There were 16 respondents in total. Of these, 11 respondents were mothers, fathers or aunts of young rural men with emergent health problems, and two respondents were Aboriginal. These two respondents volunteered information that they identified as Koori people. This was non-intentional and was not an item related to selection within the sample cohort. Three young men who identified as having emerging mental health problems responded and were selected to participate in the study. Two health industry workers who responded to media recruitment, were not young rural men, nor the family member of a young rural man with a mental health problem therefore they were excluded from the study. Table 3.1 describes the sample of participants who were selected for the study.

A screening tool was used to select suitable participants for the study (Appendix 4). Participants were selected for inclusion in the study if they met the following selection criteria:

1. A resident of rural community in northern inland New South Wales.
2. Over 18 years of age.
3. Male or parent/ significant other of a male.
4. A personal experience of psychosis or other emergent mental health problem.
5. No current Mental Health Act Orders such as a Community Treatment Order.
6. Willingness to participate in an interview or two interviews.
7. Willingness to allow digital voice recording of his or her stories of personal experiences about the research topic with the researcher.

Following this initial screening, participants were informed that there was no reward of any kind for participating. Participants were asked to provide a contact phone number to the researcher. The researcher and participant negotiated where and when to meet for the researcher to be able to provide further written information in plain language to the participant and to obtain informed consent from the participant prior to commencing an interview. All selected participants proceeded with the first

interview at this time. Thirteen participants were selected to participate in the study following the screening criteria protocol developed for this study.

Table 3.1. Participant Profile.

P	Age	Role	Ethnical background	CUP of identified young male	Employment type	S/D	I
Pp1	50-60	Mother	Anglo European	Life long	Self employed – tourism	4	2
Pp2	50-60	Father	Anglo European	Life long	Self employed – farmer	4	2
Pp3	50-60	Mother	Anglo European	Early childhood	Teacher	1	2
Pm4	23	Young male	Anglo European	Life long, escalating after 16 y.o.	Apprentice – shop fittings	3	2
Pp5	30-40	Mother	Aboriginal Koori	Mid adolescence	Administration assistant	4	1
Pp6	30-40	Mother	Aboriginal Koori	Mid adolescence	Human resource officer	4	1
Pp7	50-60	Mother	Anglo European	Mid adolescence	Administration assistant	2	1
Pp8	50-60	Father	Anglo European	Mid adolescence	Self employed – tiler	2	1
Pp9	50-60	Mother	Anglo European	Mid adolescence	Disability pensioner	1	1
Pm10	24	Young male	Anglo European	Late high school	Apprentice – tiler	1	1
Pm11	21	Young male	Anglo European	Mid adolescence	Apprentice – builder	0	1
Pp12	50-60	Mother	Anglo European	Late high school	Farm worker	1	1
Pp13	50-60	Mother	Anglo European	Mid adolescence	Administration assistant	1	1

Legend Pp, Participant parent; Pm, Participant male; CUP, Commencement of Untreated Psychosis; S/D, Siblings/Dependants; I, Number of Interviews.

3.7 Data collection procedure

Data collection for this study was achieved by using a face-to-face in-depth interview technique. Data collection was undertaken between February and August 2008. The researcher recorded reflections and memos in a reflective journal as well as field setting maps. The journal was also used as a bracketing tool (Husserl 1970; Walker 2007), to further develop rigor in the data collection process.

Informed consent was obtained from the participant prior to the commencement of the digitally voice recorded in-depth interviews. The participants were provided with a plain language information sheet (Appendix 3) prior to signing their consent

(Appendix 2) to participate and this information was discussed with the participants also at this time. Participants were reminded at the conclusion of the interview about opportunities in the local community to access counselling assistance if the interview process had brought to the fore any uncomfortable feelings for them. The participants retained the information sheet, which also contained written information about counselling support should it be needed, at the conclusion of the interview. None of the participants reported requiring any counselling assistance following any of the interviews conducted.

Two pilot interviews were conducted in February 2008 following the selection of participants who responded to the media recruitment strategy. The participants in these pilot interviews were selected because they had experience of the phenomenon under investigation, that is, they were parents of a young rural male with an emergent mental health problem which they considered might be a psychosis, and they indicated that they had struggled to find help for their son. The purpose of the pilot interview was to indicate strengths and weaknesses in the research design and planning and to refine the data collection process (Burns & Grove 1999).

The pilot interview was recorded using a digital voice recorder and then transcribed verbatim within 24 hours of data collection. The transcript was de-identified so that all references to the identity of the participants and the people they referred to was removed. Every effort was made to ensure confidentiality was upheld for the participant (Walker 2007). The interpretation of the data and interviewing technique was checked for validity by two experienced qualitative researchers who were supervisors of the researcher (Walker 2007), and who then provided feedback to the researcher indicating that the interpretation of the data were accurate. A written copy of the verbatim transcript was provided to the participants and they were asked by the researcher to read the transcript and to indicate if the transcript reflected their memories of the interviews. The participants validated that the transcript was an accurate record of the pilot in-depth interviews and did not request that any correction or changes to the transcript be made. They confirmed that the information contained in the transcript remained the information which they had meant to convey in recalling their lived experiences of being the parents of a young man with an

emergent mental health problem in a rural setting. The participants further confirmed that they were willing to continue as participants in the study.

A reflective journal was utilised to record information and memos related to the pilot interview. The researcher reflected on both the transcript and journal entries to refine interviewing style and questioning for future interviews with subsequent participants included in the study.

The researcher decided to include the pilot interview in the study, because no changes were required to the interview schedule, or the transcript and the feedback from the researcher's supervisors concurred that the interview elucidated the topic for investigation usefully, and were satisfied with the researcher's techniques (Roberts & Taylor 1998).

Between the months of February and August 2008 the researcher conducted 15 in-depth interviews resulting in 15 verbatim transcripts of data. Ten participants consented to a first interview session with one of those interviews containing two participants. A second interview session was conducted with five participants with two of these interviews conducted with two participants. Saturation of data was obtained and no further interviews were conducted. As previously mentioned, the interviews were conducted at a time which was convenient to the participant/s, and at a location of the participants choosing. The researcher considered that this was an important aspect of ensuring that the participant was emotionally prepared to talk about a sensitive topic. Walker (2007) concurs that an important feature of research design is to carefully consider the interview venue, and to include the participant in decision making about the planning of a venue location where the in-depth interview will take place.

All interviews were conducted as face-to-face interviews with either one or two participants in each interview session. At the commencement of the interview the researcher introduced herself, and made a point of sharing some personal information about herself, such as, the period of time she had been practising as a nurse and the areas she had worked in as a nurse. Divulging some personal information by the researcher was a pre-planned strategy to establish rapport and social connection. Social proximity is an important aspect of rural community culture (Boyd et al. 2008). The researcher planned to engage the participant and build

rapport quickly by drawing on this social dynamic such that social trust and reciprocity were established and the social participation in information sharing was achieved in a timely manner (Boyd et al. 2008). On each occasion the researcher was offered a beverage such as coffee prior to commencing the interview, and on each occasion the researcher accepted the offer with the view that accepting an offer of hospitality would hasten the sense of social cohesion, and trust development between the researcher and participant. This ensured that the participant would feel a sense of established rapport and was psychologically positioned to disclose their personal experiences in relation to the research topic for investigation.

At the commencement of each interview the researcher requested permission from the participant to record the interview. The researcher commenced the conversation with a reference back to the initial telephone discussion between the researcher and the participant which highlighted an aspect of the participants experience with a mental health problem. The researcher informed the participant that this information had sparked the researcher's curiosity about their situation. She then asked for the participant to share more of their experience with her. On every occasion, the conversation started with the participant speaking of their experiences from a broad perspective. The researcher then used a funnelling technique to obtain more specific detail (Smith et al. 1995). It was therefore possible to conduct an un-structured interview which provided the participant with the opportunity to recount their lived experiences. It was also possible to funnel the interview towards more specific aspects of their experiences, which facilitated the capture of rich valuable data.

The duration of each interview was approximately one hour. At the conclusion of each interview the researcher conveyed her appreciation to the participant with a hand written thank-you card which conveyed the message that the researcher considered it a privilege to hear the human stories which had been entrusted to her. The researcher verbally reminded each participant at the conclusion of the interview that their stories' would be treated with dignity and respect and that the data would be de-identified to ensure this was achieved.

3.7.1 Interview schedule

All interviews commenced with a similar open ended question such as:

> *'Interviewer: From your initial phone message you said that you have a son, and you've had some experience of an emergent mental health problem with him. Can you tell me a little bit about that?'*

All participants were asked a very similar opening question which referred back to the initial expression of interest in the study, verbalised by the participant in a phone conversation. In each case, the researcher was able to draw a vague connection to a past problem which was alluded to in the phone call, and which provided a spring board opportunity to pursue a discussion about the young male's emerging mental health problem and how they/he coped with this situation.

The interview then progressed using an unstructured funnelling technique (Smith et al. 1995:15) to pursue areas that related to the young man, and identify any barriers that might result in a delay of help seeking. The participant was encouraged to disclose whatever they felt might be relevant to the topic of enquiry. Leading questions were avoided. Prompting questions included exploring when something different or odd was first noticed in the behaviour of the young man, who noticed this changed behaviour and did the young man or family member have any ideas about if, when, and where to seek help if help was required? Participants were prompted to talk about their experiences and satisfaction with any help they enlisted, and if they encountered any barriers to accessing help to address their specific problem/s.

These prompting questions were included based on the past professional clinical experiences of the researcher and the literature reviewed by the researcher. It was important that the interviewing was conducted by a mental health clinician. The researcher was aware on many occasions, both during the interview process and in the data analysis phases of the study that having a strong clinical mental health nursing background was particularly useful. This clinical experience provided an aspect of rigor to the study. Specifically, it is well recognised that the prodrome phase leading up to a psychotic episode is often difficult to see in its emergent phases and most obvious retrospectively following the onset of an acute psychotic episode (EPPIC 1998; Edwards & McGorry 2002; ORYGEN Youth Health 2004; Wilson 2007;

Collins & Holmshaw 2008), thus the researcher considered that gathering data about recognition of onset of oddness or prodrome would be useful information which would appropriately address the research question. Duration of untreated psychosis is recognised as one mechanism to predict recovery prognosis for an individual (Gunduz-Bruce et al. 2005; McGorry et al. 2007). It then follows that a delay in accessing appropriate help to address an emergent psychosis will have an adverse effect on recovery prognosis. It was therefore important to establish the life experiences that participants had in relation to identifying, selecting and accessing any help which they were able to source, and if they encountered any barriers which, in their views, stopped them from gaining appropriate help. The interview schedule of prompting questions enabled the researcher to gather data which was targeted directly towards addressing the research topic and in understanding the lived experiences of coping with early psychosis of young rural males in northern New South Wales.

3.8 Data analysis procedure

The digitally recorded interviews were transcribed verbatim immediately following each interview, and stored as a password protected word document on the hard drive of the researcher's computer. Each interview document and each participant was allocated an identifying alpha numeric code. The files were named with date, time and location of the interview, and notes were also recorded in the researcher's reflective journal as a key to the code. All transcripts were de-identified, and the names of respondents were removed for reasons of confidentiality.

Transcripts were sent by e-mail to each of the participants for validation, and participants were informed that they could make any changes they wished. Two participants did not wish to review their transcript and none of the participants requested any changes or editing be made to their transcripts.

When analysing the data the researcher replayed the voice recording of the interviews to obtain the full meaning and emotion of the content of the interview. The researcher also re-read the transcripts to ensure familiarity with the entire interview. A focussed coding strategy was used to analyse the data where the researcher noted

early impressions of initial coding and then sifted the data using the reoccurring initial codes to examine for categories or themes which are common across data set (Smith et al. 1995).

The computer software package nVivo8 was used to code the transcripts line-by-line. Each transcript was imported as a case into a common project within the nVivo8 environment. Tree nodes were formulated and common themes were recognised across all cases. Common themes/nodes were charted and examined for frequency across cases, and this further validated the strength of commonality which was identified. All data was entered and coded by the researcher.

The combination of both focussed paper based coding and the line-by-line software assisted coding added strength and rigor to the data analysis. The themes which emerged from the data were able to be organised further into a model which described the early help seeking practices that families and young men in this study utilised as a mechanism for coping with emergent mental health problems.

3.9 Ethical considerations

Ethical approval for this study was obtained from the University of New England's Human Research Ethics Committee prior to the commencement of the study (Approval Number HE07/149) (Appendix 5) and site specific approval (Appendix 6) for the study was obtained from the Research Governance Unit of Hunter New England Health, NSW Health on 3 October 2007. Included in the ethics application was the Information Sheet for Participants, Informed Consent Form, Plain Language Flyer: '*What prevents young males from seeking help early with mental illness?*' and a prepared Media Release. Data collection did not commence until ethical approval had been obtained.

The topic of this study is a particularly sensitive topic. Mental illness remains entangled with social stigma. In particular, exploring the experiences of young men at the emergent end of the spectrum is sensitive, and especially so in stoic rural communities (Boyd et al. 2008). Such sensitivities may disincline researchers from exploring such topics and this occurrence is reflected in the lack of literature around this topic. The researcher went to some lengths to enquire of participants in a socially

sensitive manner, including limiting the study to young men who were 18 years of age and older, and who were not current mental health clients with an active Mental Health Act order for treatment, and who did not have a legally appointed guardian. Participants were selected following their initial response to either a flyer on a public notice board or local print, television or radio media related to the research. Participants were not recruited from data bases of any type, or from health services. When contacted by a potential participant, and if deemed suitable to progress to an interview, the researcher would invite the participant to select a venue of their choosing for the interview to take place. Once a location was mutually agreed on, the researcher attended the venue ensuring that no health service, or university insignia was visible to any observers on cars, or any other items carried by the researcher. This accommodated a degree of confidentiality for the participant (Buikstra et al. 2007).

Another measure to counter the social stigma and to accommodate these sensitivities was to ensure that following media publication inviting participants to self select for this study, the researcher's mobile phone voice message was changed to a simple: *"Hi this is Rhonda Wilson. I am sorry I can't take your call at the moment. Please leave a short message and your phone number and I will call you back as soon as I can."* All references to mental health which would normally feature in the voice mail missed call message for the researcher, were deleted as a consideration to this particular sensitivity and to remove any perceived barrier to leaving a message in response to the media recruitment campaign for participation in this study.

3.10 Rigor and trustworthiness of the study

Sandelowski & Barroso (2003) propose that trustworthy findings of phenomenological research design are explicit when the findings are derived directly from the data and are transformed into themes, and that these themes illuminate human lived experience. Further, a fully integrative explanation of phenomenon is achieved whereby data is transformed into the proposal of explanatory theory (Sandelowski & Barroso 2003). Evans (2003) indicates that qualitative research findings need to have an explicit evidence base. The three dimensions which determine evidence base include effectiveness, appropriateness and feasibility. Effectiveness describes the

extent to which the intervention works. While appropriateness has a particular fit with the research design implemented in this study. Appropriateness addresses the psychosocial aspects of the practical implementation of the findings and particularly the impact this has on the consumer. Appropriateness is an important criterion to assess the rigor of qualitative research. Feasibility is concerned with the practical organisational elements of implementing any interventions arising from the findings. Phenomenological research findings contribute valid evidence when they illuminate human lived experiences (Evans 2003).

The researcher was concerned to ensure rigor and trustworthiness were achieved in this study and designed the study to be consistent with qualitative methods. To further ensure validity the researcher implemented a variety of specific measures. Following the first two interviews and after transcription, the researcher sought out two experienced researchers to review the transcripts and assess the rigor of the researchers interviewing technique, and preliminary thematic analysis. Both experienced researchers indicated that the interview and analysis were sufficiently rigorous and that the emerging analysis was trustworthy. There was unanimous agreement that data collection was at a high standard. In this way credibility was achieved (Ryan et al. 2007). This was further demonstrated by the researcher returning the transcripts to the participants to ensure that the transcripts faithfully represented the participants' views. This study demonstrated dependability in the way in which the researcher has provided an account of the research process such that another investigator could feasibly arrive at the same findings (Ryan et al. 2007). Thus, auditability has been achieved. Transferabilty is established in this study because the description of the early help seeking model is a finding which can be applied to contexts outside the study (Ryan et al. 2007).

Finally, Ryan et al. (2007) indicates that when qualitative research achieves credibility, dependability and transferability, that in doing so it also achieves confirmability. This study has demonstrated an evidence base of confirmability. It was able to demonstrate validity, rigor and trustworthiness and this is evidenced by the way in which this study was able to illuminate the human experience of early help seeking. Findings were derived from the data and described as themes, which rendered a theory about early help seeking activities of young rural men and their

families. Thus this study contributes valid evidence and captures rich human experience about a specific issue (Evans 2003).

3.11 Methodological issues and limitations

Many of the selected participants nominated themselves for inclusion in this study following a media recruitment campaign. This included the publication of media releases in 'local' newspapers, screening on local television news programs in the Northern New South Wales region and live-to-air or pre-recorded talk back rural radio. Participants recruited via these mechanisms are drawn from a population of people who are interested in local media, and especially local current affairs media. People who do not have an interest in these types of media will not have been invited to participate in the study and could have been missed as the researcher further used snowballing techniques to select additional participants for the study.

The study design for this research utilised a qualitative framework to explore the research topic, thus the design did not require a large sample for the study. Participants were drawn from the geographical area of northern New South Wales. Due to this limited geographical catchment area of potential participants data was only able to be captured from a discreet regional population. Participants' responses maybe influenced by the social and geographical constraints which reflect their personal experiences in relation to the study topic. Therefore, it is important to note that the findings of this research do not reflect the general population, but rather the findings are specific and report the experiences of the individual's participants of this study (van Manen 1990). However, the findings of this research are able to report some common themes amongst these individuals which explain their experiences and may assist in the understanding of others with similar life experiences, in particular young rural men with emergent mental health problems and their families.

3.12 Conclusion

This chapter commenced with a justification of the research design and methodology utilised in this study. A qualitative design using an interpretive phenomenological

approach was considered most appropriate. Within the justification it was demonstrated how the aims of the study would fit within this qualitative research design.

The chapter identified the research methodology, specifically the setting, sample, and data collection procedure. The interview schedule was presented and discussed and the ethical issues relating to the participants were presented. Finally, methodological issues and limitations were identified.

The following chapter will present the data analysis and identify the relevant emergent themes which arose from the data.

Chapter Four

Data Analysis and Findings

4.1 Introduction

This chapter presents an interpretation of the data collected to explore the barriers that young rural men and their families experience when the young men are in early or prodromal phases of emergent psychosis. First, an explanation and justification of the data analysis procedures that were used for this study are presented. Second, the presentation and discussion of the demographic data of the participants from this study are provided. This is followed with a discussion of the findings from the analysis of the recorded and transcribed interviews.

An interpretive phenomenological approach was used to explore the barriers experienced by young rural men and their families when the young men are in early or prodromal phases of emergent psychosis. Thus, the major aim of this study was to gain insight and understanding into the experience of the young men and their families by asking: *What is the lived experience of young rural men with emergent mental health problems such as psychosis?*

Demographic data were collected from each participant prior to each interview, during the participant selection screening process. In response to print, vision and radio media recruitment of participants, people telephoned the researcher to express an interest in being included as participants in the research study. During each telephone call the researcher utilised a screening tool which guided the selection of suitable participants for the study. Participants were included in the study if they met the following selection criteria:

1. A resident of a rural community in northern inland New South Wales.
2. Over 18 years of age.
3. Male or parent/ significant other of a male.
4. A personal experience of psychosis or other emergent mental health problem within the previous two years.

5. No current Mental Health Act Orders such as a Community Treatment Order.
6. Willingness to participate in an interview or two interviews.
7. Willingness to allow digital voice recording of his or her stories of personal experiences about the research topic with the researcher.

Thirteen participants were selected to participate in the study following the screening criteria protocol developed for this study. Thus, demographic data was collected and has been presented in this chapter to describe the study sample. The researcher was interested to explore the experiences of young rural men older than 18 years of age and who did not have any current Mental Health Act Orders. Frequent hall-marks of prodromal and early psychosis phases are cognitive and mood deficits (McGorry et al. 2007). For this reason the researcher decided to include parents and family members in the respondent group. Parents and family may be reliable informants in regard to the early identification of their son's emergent psychosis, due to the declining cognitive and mental functioning of the young man. This study has found that family members are excellent observers of change, however they struggle to select mental health care help during the emergence phase of the illness. Other studies have recently found that family system functioning has a role to play in reducing the duration of untreated psychosis (DUP) (Goulding et al. 2008). Additionally, the researcher was concerned to discover the geographical boundaries of the respondents. All participants reported that they were residents of northern New South Wales, Australia. The researcher collected data regarding the number of siblings the young man had. This information was thought to be of interest as a body of research findings is developing in regard to the role that siblings play in the family system of individuals with psychosis (O'Brien et al. 2006; Gaughran et al. 2007; Leggatt 2007). Employment type was another demographic profile which was thought to be of relevance, with DUP and vocational factors, especially unemployment, also identified strongly in the literature (Killackey et al. 2006). Ethnic background was not an intended demographic factor for this research. However, two respondents identified as being from a Koori Aboriginal background. Their inclusion strengthens the transferability of this research as Koori's are an important part of the rural NSW community.

Consistent with phenomenological inquiry, the findings from this study have been presented in themes. The method used to extract themes from the data is outlined in

the previous chapter. Thematic analysis was used in this study because it enabled the researcher to understand the dynamic of lived experiences in relation to the research question (van Manen 1990). Thematic analysis was the most appropriate technique to use in this study because it is an organised technique to explore and understand the meaning of respondents lived experiences. To provide an interpretation of the respondents' narratives, the researcher undertook thematic analysis of the data to specifically understand the meanings of the emergent mental health problems experienced by young rural men and their families.

As previously stated, the three major themes emerged from the narratives of the respondents and quotations from the respondents are provided throughout the chapter to illustrate each theme. Seven sub themes were also identified. The themes and sub themes that emerged from analysis of the participants stories are as follows.

Theme 1 **Help seeking**

Sub theme 1: *Reluctance to identify as having a mental health problem*

Sub theme 2: *Vocabulary barriers*

Theme 2 **Unpredictability and social discomforts**

Sub theme 3: *Geographical issues of social stigma and social proximity*

Sub theme 4: *Emergent symptoms of psychosis and depression*

Theme 3 **Parents struggle to find help for their sons.**

Sub theme 5: *How long is a piece of string?*

Sub theme 6: *Parent roles and concerns*

Sub theme 7: *Parental emotional burden*

4.2 Profile of participants

The demographic data are presented in Table 4.1 with respondents listed in numerical order to protect the identity of respondents and to facilitate the reading of the respondents' comments.

4.2.1Descriptive overview of participants

Pp1 Mother of a 23 year old son with 'odd' and 'different' behavioural characteristics. She indicated that she has been successful in most areas of her life. Her only challenge seems to be the instability related to her son.

Pp2 Father of a 23 year old son, whom he 'always thought would have difficulties'. Pp2 is a farmer and has derived a great deal of understanding about life and coping with life's challenges from his experiences as a farmer and an 'observer'. He has 'zero' confidence in counsellors and mental health workers as a pathway for help for his son. He has lived and worked on a farm for most of his life, and has lived within a 100km radius for his whole life. He has recently commenced using a confrontational strategy ('bulldozer approach') with his son, in an effort to maintain safety for his son.

Pp3 Mother of a 21 year old son with an 'unfolding' mental illness, who currently lives at home with her. Her son has a full-time apprenticeship, in addition, he works in a part-time capacity in the hospitality industry. She has explored all the avenues that she can think of to help her son, and even so, believes that she has not been able to access the 'right help' for her son. She has expended significant thought and finance into sourcing help for her son. She is worried about what will happen to him if she is not there.

Pm4 A 24 year old young male with an emergent mental health problem. He is employed as an apprentice. He identifies for himself that he has always been slightly different to his peers. He recognises that he experiences a delay in communication with others, that he is the recipient of frequent bullying and that he battles with depression and suicidal thinking from time to time. He recently had a motor vehicle accident and has recognised some changes in his mental state following this accident. He has experienced cognitive and perceptual problems and is aware that others don't experience these same alternations

Table 4.1. Participant profile.

P	Age	Role	Ethnical background	CUP of identified young male	Employment type	S/D	I
Pp1	50-60	Mother	Anglo European	Life long	Self employed – tourism	4	2
Pp2	50-60	Father	Anglo European	Life long	Self employed – farmer	4	2
Pp3	50-60	Mother	Anglo European	Early childhood	Teacher	1	2
Pm4	23	Young male	Anglo European	Life long, escalating after 16 y.o.	Apprentice – shop fittings	3	2
Pp5	30-40	Mother	Aboriginal Koori	Mid adolescence	Administration assistant	4	1
Pp6	30-40	Mother	Aboriginal Koori	Mid adolescence	Human resource officer	4	1
Pp7	50-60	Mother	Anglo European	Mid adolescence	Administration assistant	2	1
Pp8	50-60	Father	Anglo European	Mid adolescence	Self employed – tiler	2	1
Pp9	50-60	Mother	Anglo European	Mid adolescence	Disability pensioner	1	1
Pm10	24	Young male	Anglo European	Late high school	Apprentice – tiler	1	1
Pm11	21	Young male	Anglo European	Mid adolescence	Apprentice – builder	0	1
Pp12	50-60	Mother	Anglo European	Late high school	Farm worker	1	1
Pp13	50-60	Mother	Anglo European	Mid adolescence	Administration assistant	1	1

Legend. Pp, Participant parent; Pm, Participant male; CUP, Commencement of Untreated Psychosis; S/D, Siblings/Dependants; I, Number of Interviews.

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Pp5 An Aboriginal woman, from a small rural community who is the mother of a young man who has current emergent mental health and co-morbid health problems including drug and alcohol and anger problems, and who is the aunt of several young rural Aboriginal men with problems which are similar to her son's difficulties. She has also worked in youth justice areas, and has found working in this field to be personally distressing, such that she now works in a general administrative assistance position in local government. As an Aboriginal woman she has indicated that family structure for her means that the young men in her community, and her nephews have an intrinsic role as 'sons' to her. That is, that she regards these young men as her sons. 'Family' is a broad concept within Aboriginal culture.

Pp6 An Aboriginal woman who has a community role as Aunt/Mother to young men in her community with emergent mental health problems and other co-morbid

conditions. She works as a manager in an Aboriginal non-government organisation in a rural community.

Pm7 Mother of a 23 year old son who has had a recent and first admission to a mental health unit as an involuntary patient, with a medical diagnosis of psychosis. She is keen to find help for her son who has a history of 'not quite right' behaviour, and whose mental health has declined since smoking cannabis on a regular basis.

Pp8 Father of a 23 year old son. He is concerned at the decline he has noted in his son's cognitive abilities and work ability as well as the social problems which have accelerated in recent times. He is concerned to find help for his son, and to address the legal issues which have further complicated his son's mental health problems.

Pp9 A mother of a 25 year old incarcerated man, who has mental health and developmental disabilities. This mother has struggled to find appropriate help for her son over many years, and considers that the 'system' has let her and her son down.

Pm10 A 25 year old male who has had one admission as an involuntary patient in a mental health unit following a first episode of psychosis within the previous 12 months. An antecedent to the episode was frequent cannabis use.

Pm11 A 21 year old male who has on many occasions phoned his mother to seek help for overwhelming mental health problems which he describes as 'feeling bad, very bad'. He has not had any admissions to hospital. His general practitioner has suggested that he has depression and has prescribed medication to address this problem. However, both he and his family feel that the medical diagnosis is not correct. He has periods of time where he works very hard during the day and then a second job at night. He also has periods of time where he parties frequently and gets very little sleep.

Pp12 The mother of a 24 year old son, who recognises that something is not quite right about her son. She and her son live in a small rural town with very limited access to health services. She is trying to find some help but feels nothing is available to assist her or her son.

Pp13 The mother of a young rural man. When this participant initially expressed an interest in participating in the study she inferred that she was phoning for a girlfriend. She was keen to find help, and she was unsure whether her son's odd behaviour might be related to drug use, or if it might be psychosis. She felt that there were no avenues for help in her community. She was clearly concerned about the stigma related to having a son with some problems which she could not explain well, nor find solutions for.

4.3 Transition from adolescence to young adulthood

The parents, aunts and young men participating in this study all reported that developmental transitions had been challenging situations in all cases. According to Lubman & Yucel (2008), it is now thought that the male brain does not complete its full development until around the age of 24 years. During the adolescent-young adult phase, males have a range of other life transitions to negotiate. For example, end of secondary schooling and beginning of vocations or further studies; learning to drive a car and obtain a license; legally able to consume alcohol; leaving family of origin and developing relationships for life. All of these transitional and developmental phases are crucial to the successful establishment of strong and resilient personal development and enduring success in life (Yung et al. 2006). Delays or lack of success in attaining these early adulthood milestones are not easily regained at this life stage (Edwards & McGorry 2002). Early psychosis often results in cognitive decline which adversely affects the capacity a young man has to develop and consolidate personal success and mastery of these developmental phases (McGorry et al. 2007). Thus, a lengthy duration of untreated psychosis is a significant threat to the young male's adult development.

This is also a period of time when parents and extended family are anticipating that their son will become increasingly independent and require less time and resources from the family. One parent spoke of her experiences and keenness to support her 23 year old son in moving out of home, and how she felt when it did not work out:

> *We have always joked and said 'It will be so good when you leave home – not raiding the fridge, and we can have a bit of tidiness'. 'Can you find someone to*

> *live with?'... It is not as though we want him to live on the street in a cardboard box. But, you **DO** want your children to become independent... But it didn't happen which was a bit disappointing because at that stage we thought it would be a really good thing for him to be independent. And we said, 'You could always come home for dinner whenever you ran out of food'. Oh dear. Ahh I don't know! I guess I'm really confused because he seems to be pushing us away... I don't know what has happened to him... what's making him behave this way...* (Pp1)

The difficulties that families and young men had in negotiating this transitional change in their lives were very stressful times for all of the respondents in this study. These circumstances underpinned the themes that emerged in this study.

4.4 Theme 1: Help seeking

A description of the help seeking strategies utilised by the respondents in this study is a major finding of this study. A pattern of help seeking was clearly described by all the respondents and this information assisted in answering the research questions.

> *Do young rural men and or their families know what to do when something is not quite right and when early mental health problems start to emerge?*
>
> *What is it like to try and find appropriate help in rural areas?*
>
> *How do young rural men and their families select help and where do they seek help?*
>
> *When rural young men and families ask for help, do they receive suitable/useful help?*

Table 4.2, *The early help seeking model,* below presents an interpretation of the data relating to early help seeking patterns which emerged during data analysis.

Table 4.2. The Early Help Seeking Model.

Stages of help seeking	Characteristics of helping seeking stage
Help seeking cascade ▼	Help seeking cascade commences with the stimulation of a trigger of any type. A pattern develops where help achievement is underpinned by the availability of a trusted 'other' to provide valid feedback and initiate coping.
Stage 1 **Young rural man encounters a trigger** ▼	Environmental stimuli and/or, Cognitive stimuli and/or, Emotional stimuli and/or, Social stimuli.
Stage 2 **Recognises a need to interpret trigger stimuli** ▼	The help seeking cascade progresses with the young man acknowledging a need to interpret the trigger stimuli. ***External interpretation*** - another person performs this function. Or, ***internal interpretation*** – young male is able to interpret stimuli without external interpretive support.
Stage 3 **Application of a trust filter** ▼	A trust filter strategy is utilised by the young male to select an interpretation source, either internal or external. Facilitates analysis of the trigger meaning, and deciding if a reality or validity check is needed. If the trigger poses a threat to self, than a trust filter represents a buffer for this vulnerability. Trust filter represents a self initiated protective factor.
Stage 4 **Feedback mechanism** ▼	**Primary** - Mum (less frequently dad) often the first choice as reality feedback mechanism. **Secondary** - Alternative may include selection of a counsellor who is not socially proximate and may be geographically distant, and deemed trustworthy (e.g. school nurse, vocational counsellor).
Stage 5 **Coping strategy selection process** ▼	Cascade process facilitates decision making and choice selection of available coping mechanism/s. Referral may occur at this point to one or more of the following examples: dad, sibling, extended family member, friend, mental health worker, counsellor, GP. Selected coping strategy may be solution focussed, or problem focused. Likely to be a starting point, and may lead to further fine tuning of personal coping strategies, and acquiring new coping strategies.
Stage 6 ***Tier 1*** **Implement the 'best fit' coping strategy** ▼	Application of selected strategy. Coping achieved. Deleterious outcome avoided. Or, poor outcome achieved, declining mental health, increased burden of cluster of risk/ vulnerability.
Stage 7 ***Tier 2*** **Alternative coping strategies.**	If unable to access any suitable external feedback mechanism/s: A reduction in external stimuli, for example - an unchallenging and uncluttered physical and cognitive environment may assist with facilitating appropriate coping mechanism selection from a personal repertoire/bank of problem solving resources.

Source: Wilson (2009)

The respondents in this study used these processes or stages to assist themselves or their son with gaining help in the family setting. Seven stages were noted as part of the helping process. The pathway for attaining help involved the young man first recognising the need to gain help. This need was stimulated by a trigger of some type. The trigger for needing help may consist of a challenge to cognitive,

environmental, social or emotional stability for the young man at any point in time. The respondent then decided if this challenge was something he had some previous experience of and whether he needed some assistance or not in interpreting the meaning of this trigger event. For example, one respondent said if he needed to talk to someone about a problem he would:

> *Probably talk to mum about it. Because she is mainly able to listen to me. Sometimes I talk to dad. And he will listen to me. They are just there to talk with you and yeah* (Pm4).

The researcher followed this discussion thread further and asked if it helped when this respondent talked to his parents and if they had any follow-on suggestions about getting additional help?

> *Yeah. Sometimes. And yeah she (mum) suggested talking to the counsellors at TAFE* (Pm4).

The researcher asked if this seemed like a good idea to the respondent, to which he replied:

> *Yes and no. Probably more like 'why can't you help?' Yes. I dunno. Sometimes she (mum) can help with reality...which helps a lot of times. Yep. Dunno (I) just can't handle it (reality) (Pm4).*

This respondent's comments illustrate that he was able to utilise his parents as an external filter to decide how to cope with problems, on occasions when he was unable to handle problems himself. In other circumstances he was also able to utilise an internal filter system, but he required a specific uncluttered internal environment, such as being in bed at night, to be able to achieve this as his comment below indicates:

> *Sometimes I don't seem to pick up when people are being quite derogative of me... I don't seem to realise. And yet my brother, we were at a friend's place, and I remember him coming home so upset that there were people that were supposed to be friends and yet they were doing what they were doing. I wouldn't realise until later on. And I'd finally picked up, and I was in bed on the same evening...* (Pm4).

Thus, when this respondent was able to reflect on his experiences in an environment where there was little cognitive competition for his thoughts, he could gain a better understanding of what had happened earlier in the evening. However, he could not manipulate this information during the highly competitive cognitive interactions during the gathering of friends earlier in the night. The respondent was able to understand the mechanisms happening however he needed some external prompting from his brother to set this internal filtering in progress. After some time of reflection this respondent indicated that he was:

> *Not very happy that people would be like that when they are supposed to be friends and then aren't (friends)* (Pm4).

As a result of these types of incidents this respondent found it difficult to trust others. Trusting was an important element in the very early help seeking journey for young men and their parents. Being able to rely on a trusted other person, such as parents or siblings, was clearly an important step for the young men and their families in this study. Trust was pivotal in deciding who to talk to about problems, and to decide on a next step to resolve the problem. The following exerpts demonstrate how trust was vital, especially for the practical things in life, from both the parents' and sons' perspectives:

> *People you think you can trust, you just can't trust them. So I find it hard to tell people things like at the hospital... I just keep to myself...* (Pm4).

> *...he is not a trusting person. There is a lot goes on in his life that we know nothing about* (Pp2).

> *He doesn't trust us with his feelings. But he trusts that we will feed him, and look after him, and try not to let bad things happen to him* (Pp1).

However, where a trusting relationship was able to underpin early help seeking behaviours, it was then possible for the young man to gain feedback from the trusted other and decide upon a coping strategy. The following respondent's comment reflects the important role that feedback plays in the help seeking pattern.

> *But I think people, when you have got a problem you can't necessarily sort it all out yourself. And there has to be somebody.... to talk it over with and say 'did I get this right in my mind?'* (Pp2).

In some cases the coping strategy was drawn from the young man's personal bank of previously acquired coping strategies and in other cases the respondent was prompted by the trusted other to use a specific coping strategy to address the problem. Alternatively, the trusted other was able to refer the young man to another person who may be able to help. In this way very early help seeking was achieved usually within the context of the family setting.

Discovering the very early help seeking journey that the respondents of this study used to address problems related to the mental health of young men was particularly interesting to the researcher. The findings indicate that the families in this study commenced help seeking behaviours very early, and have well established patterns for helping within the family. In contrast, many mental health clinicians would recognise help seeking as a consumer initiated activity which commences when a consumer first makes some contact at a mental health service and requests professional assistance. In fact these families had been helping successfully for years in all cases, and therefore had many helping skills already in place. Respondents did not necessarily view their helping as a mental health support initiative, and did not associate their actions with problem solving around a mental health problem.

There were a number of threats to successful early help seeking which respondents alluded to. Choosing who to talk to, especially in the context of a small rural community or town was a construct which respondents felt limited who they would discuss their heavily stigmatised problems with. The comment below further illustrates this point.

> *I don't talk about it to a lot of people. Very,* ***very,*** *very select people, who I know... (I talk to) family, and one work colleague. So fear, (I) don't want to do any more damage. I don't like to talk about it, because it is too upsetting. I don't like to talk about it because I* ***do*** *feel that there is a stigma still attached and that... (with) a negative attitude in people's minds (he) might feel that it is against him. So, we* ***never*** *let there be opportunities that he'd have to deal*

with it. I do feel however that... we can talk about it in the family... in the confines of the family. The thing is though, like it is still really, really uncomfortable. But it has become more open...(after two) cousins suicided... (Pp3).

4.4.1 Sub theme 1: Reluctance to identify as having a mental health problem

Mental health problems continue to attract stigma. Rural communities contain strong social connections and bonds (Boyd et al. 2008). Rural people are also renowned for their stoicism, especially during challenging times (Buikstra et al. 2007). The combination of these three features during the emergent phase of early psychosis and the difficulty in articulating the developing problems when symptoms are vague, impacts on the duration of untreated psychosis for young rural men. When conducting this study the researcher felt it was important to understand the experience of the respondents in relation to the emergence phase of the problem, and to ascertain if stigma, social proximity and stoicism were influential in decision making about seeking help. All of the respondents in this study experienced these features as barriers to successfully achieving timely help for themselves or their son.

The researcher asked each of the respondents: *Are there any barriers that stop you (or your son) from accessing mental health services help early?* If any: *What are they?* The researcher asked this question because during the course of her employment as a clinical nurse specialist in a public access child and adolescent mental health service working specifically with an early psychosis project for a rural and regional population in northern New South Wales, she had contact with young men and their families following a medical diagnosis of early psychosis. During this time the researcher recognised anecdotally that a variety of barriers seemed to prevent or delay clients accessing mental health services. And, those young men were first entering mental health services to address problems in their late twenties and early thirties. This band of ages reflects a considerable delay between onset of early symptoms and the successful gaining of appropriate mental health help. Thus anecdotal information gained during the course of the researcher's exposure to these

families provided the researcher with an opportunity to explore if any strengths or threats to good mental health and coping with emergent mental health problems existed. The researcher felt that if the lived experiences of the young men and their families could be better understood, then this information might assist in designing prevention and early intervention mental health care service to better capture young men with emergent psychosis earlier in the course of the illness trajectory. Further, that any gain towards timely engagement of young men towards appropriate mental health service provision early in the morbidity profile would have benefits which would be likely to include a shorter and more successful recovery phase.

From the conversations with the respondents in this study, it quickly became apparent that none of the respondents initially identified with having a mental health problem. For some of the respondents the awakening that the problem was a mental health problem did develop, but not until the symptoms and difficulties associated with the symptoms had advanced to become disabling and dysfunctional for the young man and in family life.

One respondent continued to be reluctant to identify with having a mental illness, even though he had experienced one admission as an involuntary client to a secure mental health unit. He considered that he had no choice but to do what others said following his discharge from hospital, and that life would be easier for him if he just followed the direction of those offering to help him. He remarked that *'counselling was unnecessary but it kept everyone else happy' (Pm10).* He continued to doubt that there was any link between his mental health and his premorbid use of cannabis. He continued to believe that his idea of life being sustainable on mars via a tube of oxygen being supplied by the earth was logically viable. He did not consider that he had a mental illness and could not explain why he continued to take medication for a mental health problem. Often in clinical settings these types of delusional thoughts and poor insight are recorded as part of a comprehensive mental health assessment. However, as a respondent in this study, these were the present lived experiences of this participant, and need to be considered in this light also. What is clear from discussions with this respondent was that he did not identify that any of his recent difficulties had any relationship to a mental health problem. He was not willing to include himself as having a mental health problem.

Another young male respondent recognised that he had concentration problems and trouble getting things down on paper. He called this circumstance the 'delay'. This delay was alluded to throughout his interview, and was a feature which he accommodated in everyday life. He didn't recognise that he had any mental health problems just a 'delay'. An exerpt from his interview reveals that he was experiencing symptoms of mental illness, yet he described the symptoms as interesting occurrences which he couldn't explain.

> *I don't know why I saw it, but I saw it. I saw this girl as I was walking... I had to look twice because I thought she was a ghost with a beard. It was just like crazy. I don't know why I saw it, but I saw it. Really strange things. And sure it was strange, but interesting to think about later* (Pm4).

And, this respondent also battled with suicidal thinking, but did not consider that anyone other than his mum might be able to help him deal with these thoughts.

> *I have gotten to points where I really just wanted to end it. Kill myself... and there are times when I feel really, really sad and just lethargic and just want* ***everyone*** *(said with emphasis) to leave me alone...* (Pm4).

Thus, this respondent recognised that he experienced strange thoughts and sometimes wanted to kill himself, yet he did not equate these two features as a mental health problem. To him the problems consisted of seeing something strange, and of feeling really sad, yet to a mental health clinician these features would be identified as mental health problems amenable to mental health treatment modalities. Impairment was apparent to a mental health clinician however the anticipated subjective level of distress experienced by the young man may not have been acutely experienced by the young man. A gap existed in the way respondents identified problems themselves and the way in which mental health clinicians would interpret these same problems.

Other parents looked for a point-of-origin for problem behaviours exhibited by their son and they were confused about whether it may be a mental health problem or whether the problem/s could be attributed to some other origin such as drug use. An explanation of point-of-origin other than a mental health problem was the focus of the attention for these parents. Even though their son had received a formal diagnosis of

early psychosis, they still questioned if this was indeed the case. The following comments by these parents demonstrate how they rationalised their experiences.

> *He was always a normal boy, normal childhood. He got involved with drugs, cannabis, and got in with the wrong sort of kids (*Pp7).
>
> *I wouldn't allow him to have his druggy friends in our home. So I suppose this is my fault in part. But you have gotta have standards and you hope your kids will follow your standards* (Pp8).
>
> *He had a fall off his bike...last year...in hospital with concussion* (Pp7).

Respondents did not readily identify as having a personal mental health problem in all cases.

4.4.2 Sub theme 2: Vocabulary barriers

Exploring the sub theme of a reluctance to identify with having a mental illness gave rise to another barrier to accessing mental health care early: a vocabulary barrier. The symptoms of early psychosis are vague and emerging. They are not crystallised into a clear cluster which informs the basis of a diagnosis. They are formative and developing over a period of months and years, and the insidious increments of change are not obvious. Early psychosis is often described as something not quite right, and that you can never quite put your finger on what is wrong. Yet there is an awareness by observers that something is not right. However, there is not a vocabulary which adequately conveys the problem. Without the vocabulary to describe and communicate the problem, the problem is not easily able to be addressed. This lack of vocabulary to explain the problem is a barrier to initially choosing a helping mechanism. This may explain why young men and their parents don't access mental health services earlier in the morbidity profile. It simply does not occur to them as an appropriate response to a vaguely described oddness. This was illustrated by the following parent's comments:

> *He had always been a different child... a separate child. He was just odd from the very beginning. My husband says from about the age of eight he expected our son to have problems. And he has been a very lonely child his whole life.*

> *But one day in year eleven he came home (from boarding school) and said he couldn't go back. So, then we knew that things were changing* (Pp1).

This respondent could see a change from a baseline of oddness developing for her son, but she couldn't conceptualise the growing bank of symptoms as a mental health problem. Her next step at this point was to discuss the problem with her girlfriends. Together she and her friends thought it might be some kind of a learning difficulty. For months her son's behaviour had become increasingly odd, he would isolate in his bedroom for long periods of time, briefly emerging for meals, and retreating again as soon as possible. At the time of the first interview the oddness had escalated to a crescendo. She was still unable to articulate the problems as mental health problems and it did not seem logical to pursue mental health treatment. She responded to the media release calling for participants for this study and remarked that she didn't think her situation would be of interest to the researcher because her son was behaving oddly, but he didn't have psychosis, however she was happy to participate if it might be helpful. This respondent was a rich source of data for this study because in fact her son had very clear symptoms of psychosis which was immediately obvious to a trained clinician, however not at all to her as a parent.

This was of particular interest to the researcher. A vocabulary was not apparent to articulate the emerging problems which the young men experienced. It was then a logical progression that because of this great difficulty in expressing the confronting problems, it became increasingly difficult to decipher where to access help. A major vocabulary barrier existed and for this reason parents and young men accessed a range of help sources which were unrelated to mental health.

One respondent remarked about a source of help that he had used to try to find help for his son. He was especially concerned that his son might have become involved in a situation that might compromise his personal safety because he had become involved in an online relationship and was planning to travel overseas. The father considered that a risk of human trafficking existed and considered that he had to take a 'bulldozer' approach keep his adult son safe. He explained:

> *...legally he is an adult. There's nothing legally we can do to stop him from doing anything... and you talk to your solicitor about it and he says you can get*

> *him* ***sectioned*** *(said with emphasis), you can't stop him from taking off and going to (overseas location). He could still apply to go overseas. He is totally out of your hands. He said all you can do is talk, is keep the lines of communication open. But it is time for me to get back in and eyeball him (son)...he certainly has changed a lot* (Pp2).

This father was able to see a clear problem that his son may be at risk of being enslaved overseas. He recognised a threat to safety and his response was to gain legal help to solve this problem. Even though 'sectioning' was referred to, a term which usually means to enact the mental health act and detain a person for formal mental health assessment against their will if necessary, mental health help was not seen as a solution to the underpinning mental health problem. The vocabulary was around doing whatever it would take to ensure safety, not about treating a mental health problem. Another respondent in this study also had spoken to the family solicitor about her son. This mother had not sought mental health treatment for her son either. These two respondents reminded the researcher of similar anecdotal stories from clinical practice settings. It is the experience of the researcher in clinical settings that hearing a recount by a parent who reports consulting a solicitor prior to commencing mental health treatment is not an uncommon story. Even so, this opportunity for interdisciplinary collaboration is not a feature of usual mental health care planning. However, in this study, a number of respondents included consulting solicitors as part of their help seeking sequence of events.

The terminology that respondents used to describe an actual or emerging mental health problem was also elucidating. Terms such as issues; problems; difficulties were common throughout the transcripts. These terms are vague and can encompass a broad range of phenomena, which perhaps makes them well suited to explaining such a difficult concept as emerging psychosis. There is also some self protection offered by the use of these terms which are less stigmatised then mental health terminology. However the non specific vocabulary is rather ambiguous and this is problematic in identifying emergent mental health problems especially where it acts to soften or reduce the intensity of the problem. The following exerpt helps to illustrate this ambiguity of having 'issues'.

> *Our nephew...he had a couple of issues. He saw a couple of suicides where he cut the people down. He had domestic and family violence where he had seen his mother getting beat up. He had a lot of issues. And with the drug and alcohol. When he became a teenager he got involved with the police. He kept going to court. They tried to get him into drug and alcohol counselling, but the counsellor was on maternity leave. And there were no other options available. This young boy, he had* ***issues*** *(said with emphasis). He just never left home, he just played (video) games and things like that...*(Pp5).

This respondent went on to explain the oddness that had been developing in this young man's life, how he seemed withdrawn, talking to himself at times, and his being highly suspicious of others. However it is easier to count the more overt problems like drug and alcohol use and witnessing various adverse events, but it is not so easy to find a vocabulary to explain the vagueness of emerging mental health problems. The mental health issues can be lost in a sea of overt obvious issues, and thus mental health treatment is not obtained. Sadly for this young man, living in a small country town with few services, even though he had been referred by the court to receive drug and alcohol counselling, he was in fact unable to access this because the only counsellor available to this community was on maternity leave. The drug and alcohol counselling may have been an opportunity to gain mental health specific help also, but this did not occur. Thus, another barrier identified in this study is the lack of locally available services in small rural communities, which adversely affects the duration of untreated mental illness and protracts any potential recovery period adversely.

4.4.3 Summary

Families and young rural men are experienced in seeking help and providing help during the emergence of mental health problems such as psychosis. Help seeking is a major theme which has emerged from the data within this study. During the course of this study it has been evident that help seeking is well established during the prodromal or early phases of psychosis. The help seeking cascade describes the complex set of events which occur for these young men and their families in regard

to help seeking within the confines of the family environment. Further, families indicate a preference for helping each other in this context.

Two sub themes emerged from the data which are embedded in the help seeking framework. The first sub theme is that young men and their families are reluctant to identify with having a mental illness. This may be attributed to the insidious and vague features which characterise the onset of psychosis. Alternatively, it may be that the more overt and more easily described immediate problems draw immediate attention and require resolution, thus shadowing the mental health problems which are emerging. An interesting finding from this research was the utilisation of legal practitioners as external helpers by family members.

The second sub theme which emerged describes the vocabulary barrier that exists for the vague and slow onset of mental health problems experienced by young men. The paucity of vocabulary to adequately define the difficulties which young men and their family were negotiating made it especially difficult to first describe the problems which they faced and then to select appropriate external help such as mental health care assistance.

Thus, help seeking commences very early within the family setting. The problem requiring help was not identified within the family as a mental health problem primarily because a vocabulary does not exist to adequately describe the emergent problems which are forthcoming. Families in rural communities have little opportunity to develop skills in recognition of early mental health problems because there are very few locally available services in these communities. Exposure and awareness of emergent mental illness and it's appropriate treatment is not demonstrated in local communities and therefore is not part of the local conversation or dialogue when solutions to vague problems are required.

4.5 Theme 2: Unpredictability and social discomforts

A second theme to emerge from the data was expressed as the unpredictability of the young man's behaviour and the social discomforts that were associated with the changing and declining behavioural patterns exhibited by the young men, especially as they were experienced by family members. The respondent parents recognised

that adverse changes were occurring for their affected young man and that the predictable sequence of a young man taking on increasing personal responsibilities and successfully negotiating these added milestone responsibilities was diminishing. This situation defied logic and came at a time when the parents and young men felt that they should be able to cope with increasing autonomy. Yet a diminishing capacity to be autonomous was actually occurring. It was a significant blow to the young men and their parents when increasing supervision and help was required by the young men.

Two sub themes further depict the complex dynamics of the second major theme. Sub theme 3: Geographical issues of social stigma and social proximity and sub theme 4: Emergent symptoms of psychosis and depression. The unpredictable behaviour and associated social discomforts theme will be presented and then followed by the description of the two sub themes which further strengthen the main theme category.

One mother recalled the challenges represented by unpredictable behaviour and the discomfort experienced by family members as they attempted to deal with these challenges. In this instance the young man had developed an emotionally attached online relationship with a male from another country. The young man had only revealed snippets of information to family members. The family had a longstanding coping arrangement whereby the family agreed to share information with each other which related to the odd behaviour of their son and brother in an effort to manage any imminent risks. In the exerpt below, the family had identified that the son and brother was clearly the victim of predatory internet abuse. This was obvious to the family, however, the young man was oblivious to the risks. The family was greatly alarmed and the discomfort levels within the family were accelerating rapidly. The concerns were multifaceted and stressful, a clear burden for the family, yet the young man remained relatively oblivious to the discomfort levels experienced by his family members.

> *...he was planning on travelling to (another country). To meet this person (internet relationship) and bring him back to Australia.... we were worried... Finally his brother.... had had enough and he said to E, he took E aside one afternoon, they had both come home from work, he took E aside and really*

> *gave him a roasting. "Look this is absolutely stupid, we are all worried sick and mum and dad know that you have told W (sibling) one story, B (sibling) one story and C (sibling) one story, and us part of the story" And he said "You've just got to talk". But he STILL didn't. He still didn't... that evening he was just going to spend time in his room again and on the phone to this Ian person (overseas). I hate to think what his phone bill is going to be like...(Pp1).*

At this point the mother was prepared to risk the trust which she had built with her son in an effort to maintain his safety. She was prepared to reveal to him that the family had shared information with each other in regard to what each of them knew about his plans. She did this because the family stress levels had reached a threshold where no other alternative seemed viable.

> *I went in and said, 'We want you to come out (to the lounge room) and tell us what you are thinking of doing'. Simply because it is so darn stressful (Pp1).*

The family had labelled the overseas identity as 'Internet Ian'. This labelling seemed to help the family to package the larger problem that they saw as looming. The problem was a complex set of events, which was difficult to articulate to each other, however by creating a category or label for the problem they were able to package the problem in such a way which communicated within the context of the family, the whole problem. It also enabled the family to distance themselves from the social discomforts of the situation and to attempt to approach it from an objective stance. When they did confront the young man with their corporate concerns it was clear that he did not perceive the risks which the family members had been able to identify. It was evident that the young man was especially vulnerable to predatory online invitations.

Thematically similar unpredictable behaviour of young men was a constant source of underlying stress and discomfort for other parents in this study. Parents reported fearing physical harm to family members. Mothers reported a sense of needing to monitor safely levels and diffuse potential flash points if they recognised a heightened risk of harm. This burden of care experienced by the mothers and aunts was pivotal in maintaining balance and a sense of harmony within families. The following respondent's comments further illustrate this theme:

He is so unpredictable. I always have to see what he is like before his father gets home. His father sees things in black and white. He is more likely to talk to me. I don't know what the problem is. But, it's got to the stage where I locked up all the knives in the house because I was frightened. I don't think he would ever do anything to hurt me, but he gets this look in his eyes. I don't know what it is (Pp7).

He got to the stage where he was coming home and threatening Mum's life. Putting knives to her throat...we would ring the police and dob him in because we were scared for Mum's life... he was psychotic (Pp5).

...he would smash walls...he was very, very violent...he is on the run at the moment (from the police) (Pp6).

Families reported coping with some very difficult behaviours and circumstances where personal safety was compromised. The researcher asked respondents what they thought might help at this point. All of the respondents considered that it was important that the young man had someone to talk to, and if such a person was available to the young man, then this might help alleviate the unpredictable behaviour and the discomfort associated with coping with the young man's behaviour. The following quote by a parent encapsulates this perceived solution.

I guess just someone to talk to. He had lots of issues... (Pp5).

Another mother indicated that her experiences had been a battle, and that she felt she had not been able to find help to alleviate the constant battle to cope as illustrated in her comments:

He and I have been to hell and back... it has been a very tough battle (Pp10).

4.5.1 Sub theme 3: Geographical issues of social stigma and social proximity

One aspect of social discomfort was further clustered in a clear sub theme which related to the geographical issues of social stigma and social proximity. It is uncomfortable for the young men to differ from the norm of other young men in their

rural settings, and it is socially difficult for the families of the young man who encounter the stigma related rebounds associated with the close social proximity which is part of the lived experience of residing in rural communities. The following comment succinctly illustrates this tension.

> *Well I think 20 year old rural men are out and about. Well, my son is. He plays footy and works in a pub and goes out and... so having to admit you know that there is a stigma there, you know that he is not well. So um well on three different ... crisis points (occasions) he's seen someone and now* ***he is so*** *(said with emphasis) anti-counselling that I don't know if he will ever go back (to counselling). He is very anti. So that for me is a very sad moment (Pp3).*

This parent indicated that maintaining a social standing was highly valued by her son, and when he had seen a local counsellor and not had helpful outcomes, that this circumstance effectively burned a bridge and made it harder for her to talk to her son about future consultations with local counsellors. A particular issue was that the counsellor had to cancel an appointment with the young man. He considered this to be a betrayal of some type and this simple act was sufficient to stop him from pursuing this type of help again. This represented a barrier to accessing help for his mother, who felt that her already limited helping resources had diminished further.

This unpredictable behaviour along with social dysfunction are recognisable features of emergent psychosis (EPPIC 1998). Parents and families did not immediately recognise the insidious emergence of psychosis as a mental health problem, however they certainly found themselves in circumstances which they could not easily explain. Sub theme 4: Emergent symptoms of psychosis and depression will further highlight this 'hard to explain' problem.

4.5.2 Sub theme 4: Emergent symptoms of psychosis and depression

One young man could retell some unusual experiences that had happened to him. He did not see that his unusual experiences might have a mental health or illness

context, rather, just that they were different experiences. His following comments outline one of the unusual experiences which he had encountered.

> *...I don't know why, I had washing in the washing machine....I had my clothes that were being washed and I was putting them on the line. It was quite dark at night, like one or two in the morning. And I was putting the clothes on the washing line and I thought I saw someone going into the laundry and I didn't see their face, the lights were on in the laundry (laundry was the type that was a detached large room from the rest of the house). And I saw them go in and thought. OK. This is strange. Um, I carefully walked up, bravely walked up, stupidly or whatever, and started to call out 'hello' and 'is anybody there?' and 'can I help you?' and had a look inside and* ***no one!*** *(said with emphasis and surprised tone). And I had a look behind everything that I could look behind and in the cupboards and thought 'this is strange' and thought 'nope!' Time for bed! Switched all the lights off and went back inside and went to bed. Yeah it's...different* (Pp4).

He indicated that these types of experiences were unsettling, yet he was still convinced that it was a real experience. His conclusion that it was 'different' was his way of coping with the phenomena, and underwriting its validity even though he had no evidence of its validity. These early experiences of unusual and unpredictable occurrences were uncomfortable, and he did not feel he could talk to others freely about these occurrences. Occasionally he would mention them to his mother in matter-of-fact ways, but indicated that she had no explanation for the event either.

Other respondents indicated that the emergence of depression and social isolation were factors that impacted on the social functioning and day-to-day well-being of both the young men and of their families. The dampening of mood within the internal structure of the family resulted in a constant level of mood surveillance by parents who would attempt to interrupt downward spiralling of depressive behaviours by adjusting family activities to accommodate the uncomfortable feeling experienced by their son. Thus, the emergence of psychosis like symptoms and depression were part of a larger theme of discomfort.

4.5.3 Summary

The second major theme described the unpredictable behaviour that the young men experienced and the social discomfort that followed this behaviour for both the young men and their families. The lack of insight demonstrated by the young men in regard to looming significant problems resulted in significant social discomfort for the family both as a closed unit and with some discomforts spilling over into local social networks threatening social reputation and igniting social stigma. Often a discomfort threshold had been reached within the family unit which instigated a more aggressive authoritarian phase of problem solving. In the first major theme outlined in this chapter it was clear that trust was an important aspect of help seeking. However, once the discomfort threshold has been surpassed, trust is forfeited in favour of ensuring personal safety for the young men and others within the family. Trust was highly valued by the young men and parents alike, so forfeiting this trust came at a high price and only when no other problem solving strategy was resolving the immediate safety problem.

Social standing within a rural community is of importance to rural people. Sub theme three described the balancing-act that families and young men find they need to manage in regard to social stigma and social proximity. These two factors impact on decision making about accessing and maintaining external help, especially if mental health help is accessed. Sub theme four described the respondents' experiences of the emergent symptoms of psychosis and depression which were uncomfortable problems of everyday living for the families and the young men.

Social discomfort and unpredictable behaviours place a social management demand on young men and families. At times, these demands can be overwhelming especially for the family, and result in a burden of care and responsibility which cause parents to extend their help seeking boundaries, even if the personal cost to relationships is exceedingly high.

4.6 Theme 3: Parents struggle to find help for their sons

The final theme which emerged from the data was that parents found it difficult to ascertain what type of help outside of family support might be available to them, and where they could ascertain helping services. It was especially evident that parents did not always identify the emergent problems as a mental health problem, and not even a general health problem in some cases. The researcher asked all respondents where they thought they might get help, and who they would select as a helper. The responses illuminated the theme of struggling to find help.

> *I **don't** (said with emphasis and a hint of puzzlement or frustration) know! I don't know who to go to... (Pp1).*

Respondents also indicated that when they did select or trial a helping option offered by some type of professional, that they were not always able to negotiate access easily. Some reported being very dissatisfied with services which they had utilised such as the parent's comment below.

> *And so, now, my confidence in these so-called 'help' people is ZERO (said with emphasis). Anyhow, because I think that they are concerned about this thing NOW. This kid is extremely depressed and all the rest of it, and so what we do is look at the here and now. But, we never give them the bad news that 'hey – you've gotta make a whole heap of changes'. Right? (Pp2).*

This parent could not understand why the health professional who had consulted with his son did not express strongly to both the young man and his family that changes to his lifestyle and life approaches would be necessary. This seemed needed by the parent, yet he considered that the tact the clinician was taking was a gentle approach which failed to rock-the-boat sufficiently and initiate much needed change. This parent coined the term the 'bulldozer approach' which was his way of dealing with problems that needed to shift. Thus the slower and more subtle approaches by clinicians did not appeal to him, and did not meet his urgent needs to see change implemented. This was a particularly interesting consideration, especially in light of theme one and the help seeking pathway which was identified as being utilised by families. The experience of this father was that he had been helping his son for many years, and for him to witness what he thought was a delayed and unhelpful approach

to helping was not seen by him as useful or valuable. This led to a great deal of frustration and was clearly a barrier towards accessing professional help. The idea that he had expressed having zero confidence in health professionals was also a significant barrier to identify within this study.

Another parent told of her experiences in accessing professional help for her son and for another unrelated young man for whom she found herself in a helping role. This parent and helper was a rich source of data for this study. She was able to articulate in clear terms the struggles that she had endured in accessing help. She indicated firstly that rural areas have a lack of accessible services as her comment below indicates:

> *I don't think there is a lot of support in the rural areas. I know ...it should be better (Pp3).*

This woman worked in an environment where she was in regular contact with other rural young men. Towards the end of an in-depth interview with her, the researcher asked her if there was any other information which she considered was important to relay to the researcher. It became apparent that she was involved in helping an unrelated young rural man and that her helping role in that regard was also usefully informative for this study. She was able to compare her role with her son and her role accessing help for someone who did not have family support for helping with problems which she considered were similar to the problems faced by her son. Thus she was able to retell experiences that revealed the struggle that she and her son had endured as well as the struggle she had experienced helping someone outside her family also. Her comments below record her experiences in this regard.

> *I am also involved in another situation where I had to take a student to hospital... he hasn't got a GP... He rang up (a medical centre) and said 'I need to see a doctor'. And (was given the next appointment available) 'two weeks from Friday'. (He told the medical centre staff) 'Well don't worry about it.' He had a gapping cut on his arm here (indicates slashes to an interior aspect of forearm) that he has done to himself and he calls you know... cause he hasn't got a mother like me. To get an appointment to see a GP...he is really depressed. He has no support or no, you know, so one of the teachers rang*

> *the GP yesterday and said 'I'll just keep ringing you until you can get this man an appointment, he's really, really, really unwell.' (Pp3).*

The two week delay was an unacceptable delay from the woman's perspective. The young man was not able to articulate an urgency to the gate-keeper role of a medical centre receptionist, and thus was unable to access timely help. The woman was especially concerned that the young man indicated that if he could not get an appointment for several weeks, then, it was not a personal priority for him. Even when staff members from her workplace attempted to intervene and gain help for the young man, it was still not forthcoming. The logical help access point became a barrier to accessing help. The next step in accessing help for this unrelated young man was for the respondent to attend the local hospital with the young man to seek help. Her comments continue below.

> *...(I) took him to outpatients and sat with him for two hours which is not good you know, but better than some poor people wait and they saw him and fixed his arm and said 'off you go to your GP'. And he's BAD, I tell you he is really bad. His cuts – he has cuts from top to bottom and you know ... they are either untrained or uncaring those people that go through that system (Pp3).*

Thus after a substantial wait, as an unrelated support person the respondent was only able to access the physical assistance related to dressing a wound, yet the more concerning issues to her were left unaddressed. The respondent found herself in a helping role which she considered should have been passed on to the health service, especially in light of the lack of family support this unrelated young man had access to. She saw his situation as very vulnerable and was stunned that even the help that was available in a rural community was effectively unavailable to this young man in great need of help.

> *... he has got no family .... he's not in an emotional state to ... You know. Like the personality that you know, they try to ring the doctor and they say 'No can't fit you in for a fortnight' and then you leave. Then, 'Oh no I'm not that sick'. But you are really sick. It is very hard to access even what is there. ...I don't think you should have to get this bad before you can access help. There are terrible waiting lists... (Pp3).*

The respondent went on to further relay her experiences of gaining help for her own son outside of the public health system. She indicated strongly that she had no faith in the capacity of the public health system to be able to provide adequate help for her son. She considered that she needed to ensure that she was positioned financially to access the best help possible for her son. Her experience of the new medicare rebates available was also a rich source of data in regard to actually accessing what may seem like a national strategy to provide diverse and innovative mental health service to rural communities. However the experience that she and her son had was less than positive. It was especially interesting that this respondent went to some effort to articulate her views as positively as possible. She indicated that the public perception which she seemed to share was that the service provision conceptually was a positive initiative, although her personal experience of it was far from positive.

> *I am in a fortunate financial situation. We have private insurance. But to see a psychiatrist is $550. Now there is a Medicare rebate. But you gotta pay upfront. The average person would NOT have those resources. Also, we've actually accessed the government scheme ...you can see someone and get a rebate. We used that with a counsellor. It is a LONG and complicated process that I don't think should have to be there. You have to go to your GP. They have to do a plan. And I suppose that is making it all – so you go to your GP, they do a plan and it has to be registered. You have to have one for each professional (and) you have to know the counsellor you want to go to. You have to get referred to the psychologist. You have to do another plan. It's a lot of time... but with that you can use six visits that are Medicare rebatable. My understanding (from the media portrayal) is that the scheme has been well received. But, I am just reflecting on what it is like to me.... I think it is complicated for me, so it must be complicated for others. I am well resourced. I have a good basic education. I have a good lot of experience. I am really struggling with all of this...it is very difficult. Um...so maybe it is a problem for everyone (Pp3).*

Within the main theme of parents struggling to find sufficient help, three sub themes were further identified: Sub theme 5: How long is a piece of string; sub theme 6: Parents roles and concerns; and, sub theme 7: Emotions. Each of these sub themes articulated with the over-riding struggle that parents have in finding suitable help.

3.6.1 Sub theme 5: How long is a piece of string?

Parents wondered how long they could cope with the burden of care and the difficulties arising from helping a son with emergent problems which were increasing in intensity rather than reducing as might have been anticipated amongst young men without emergent mental health problems. One mother reported that she could see matters building and getting worse over time.

> *...his odd behaviour seems to be escalating...he has changed. His behaviour has changed. His attitude has changed... I am very concerned that he is going to (participant starts to develop tearfulness)...to crack (her voice quivers and softens to almost a whisper). He'll either run away, or do something really rash. He'll chuck in his job... end up in a heap (Pp1).*

She was concerned that a threshold was nearing whereby she might be unable to help her son, and was fearful of what this might mean for her, her family and her son.

> *... I won't be able to do anything. Just too many disappointments building. I might be wrong. He might be able to control himself. But we have not welcomed his (recent) acclamation that he is gay...Things, everything just seems to be very negative at the moment and I do wonder where it will go from here... it bothers me that he might suicide. Yeah (quiet quiver in her voice). And he doesn't have anyone he can talk to. He doesn't have friends... or anyone else...it comes down to how long is a piece of string mostly (Pp1).*

Other parents echoed the concerns raised in the above comments, about the future and the unknown duration of time whereby their sons would require extra help. All parents in this study were concerned that life might become worse and not better for them and their sons. All parents had grave concerns about the possibility that their sons might either suicide and/or harm others, and that they may not be able to prevent this from occurring.

This sub theme identifies the helplessness that is experienced by parents and the powerlessness surrounding the escalation of problems, the vulnerabilities and inherent risks including the possibility of suicide and the frustration of not having

someone to intervene. The phrase 'how long is a piece of string' implies loss of hope and uncertainty on the part of the mother. This circumstance is a significant threat to the help seeking pathway which has previously operated in the family context as described in theme one of this chapter.

A second sub theme emerged which identified the role and concerns that parents had for the sons.

4.6.2 Sub theme 6: Parental roles and concerns

The researcher was interested to learn about the roles that the parents played in supporting their sons. The parents recounted their experiences and functional patterns were evident in their stories. Within parenting partnerships different and complementary roles were evident. Some caring functions were delegated to other family members also, which created a caring and supportive network for the young man and for the members of the family. It was clear that the young men were not always interested in being the recipient of the caring functions, however, in all cases the caring functions were provided regardless of the young man's interest or engagement.

The burden of care that one biological mother had for her son was more keenly felt by her then by her non-biological partner in her view. She expressed concerns for the future of her son. She considered that his wellbeing may be jeopardised in the future if she was not available to help him. The baseline function of monitoring his wellbeing was a vital tool to know when to initiate timely help and support and ensure that decline did not occur. This mother felt that no one else would be equipped to take on this role, and that the burden would need to remain with her. Too much was at risk in her view to hand over such responsibility, even to a trusted close sister, who volunteered to help.

> *I am really worried about who'll look after him, who'll see him everyday like I do, who will ring him everyday like I do? Just to check he is alright. And even if someone does that, will they notice all of the (types) of things I do?... if he moves out of home, how will I manage that? How will I know he is OK? But at*

> *the same time letting him be a normal person. That is a really big challenge... I worry when I am away from him (Pp3).*

The role of the mother was identified as a special role by a number of respondents. For one respondent this had a religious value, but for several other respondents the mother-son bond and its inherent responsibility took on a family cultural value.

> *I was brought up in a very traditional catholic family... the mother is very important in your family, and also in our faith. You know it is a very, very important part. So you know we look after our mother and hope that they look after us... it is a big part of our life (Pp3).*

This strong belief system reinforces the responsibly that the mother has to help her son and articulates this help as an obligation which is not optional, thus the burden of caring is also reinforced as is the embedded shared subjective life journey and shared experiences.

A father's perspective was seen to be more objective, with a more analytical approach to problem solving. One father had learned observation skills working in the agricultural industry and applied these skills to the context of caring for his son in complementary partnership with his wife. Farming philosophy underpinned his functions and role in helping.

> *...you've gotta be an observer, observer of body language, environment.... the whole works... I was trained by my father. When I was seven or eight he'd say 'come on, we're going for a drive... you can open the gates for me'. After you'd gone through a paddock and before you got to the next gate he'd say: 'Hold on, tell me about the stock? What was the water like at the dam?' He was training me....to look at environmental things... (Pp2).*

This father applied the same observational strategies to his son's circumstances.

> *I just gotta watch his body language. And all the rest of it. And I will be able to tell whether he is honest... or whether he's putting up a story with something totally different going on behind (Pp2).*

Interestingly the father considered that he could assess his son, and analyse problems with a view to finding a solution. However he could only do this within a

one-on-one framework with his son. If his wife was present, he claimed that the dynamic was very different, and he was often unable to progress to a solution phase in helping.

> *I need to do it one on one... I have to direct the conversation exactly where I want it to go. As soon as (mother/wife) arrives, she'll say: 'Oh, is it OK if I join in?' and of course you have gotta say 'yes'. But it breaks the thread of where you where trying to go... (Pp2).*

The final sub theme which impacted on parents' abilities to cope with the struggles of helping a son with emergent mental health problems was the emotional enmeshment which saturated the struggle context.

4.6.3 Sub theme 7: Parental emotional burden

Emotional attachment is a healthy component of parent and child relationships. However it underpins some struggles also. All the parents in this study described their experience of the emotional burden they experienced. The comments of one mother, echos the experiences of other respondents, and demonstrates how her emotional attachment to caring for her son had become stressfully entangled in her own mental health and wellbeing.

> *It has always been a very emotional thing for me. (My sons) problems have always bothered me, but, yeah. I've reached the end of my string (tears and sobs). This sounds horrible, but, I wish he'd just go away... it is pulling our family apart...we all tippy toe around his issues. His brother is spending so much time anywhere else BUT home. I have got to the stage where I think 'if you won't take any notice, just go off and do your own thing'... I cry... (Pp1).*

The emotional burden of caring for and trying to help a son with unpredictable behaviours at the emergent phase of a developing mental health problem is profoundly stressful for parents. The hopelessness that accompanies this burden is overwhelming at times for parents, as demonstrated by the respondent comments in this sub theme.

4.6.4 Summary

The final theme has described how parents' struggle to find help for their sons'. Parents do not equate the problem cluster experienced by their son and family as a health matter. Finding help was very difficult for all the respondents in this study. Often the respondents could recognise something was wrong, but finding a helping professional was not easily achieved. Resoundingly respondents did not know where to look for help. When they did find help, their confidence in professional helpers was not very high. They reported a great deal of dissatisfaction in their dealings with mental health professionals. The respondents indicated that they considered there was very little in mental health service provision in rural communities and that they lacked helpful support when they needed it. Parents felt that accessing health services, general or mental, was extremely cumbersome and that public health services were unacceptably cumbersome to the point of repelling would-be clients. Parents felt that more should be available, and some respondents reported that it was important that they could afford to access private mental health services for their sons. However, even the new government initiatives offering rebates for a variety of mental health consultations from a range of disciplines posed unhelpful barriers to accessing and maintaining professional help.

This lack of professional help achievement at a local level placed significant burdens on families to care for their sons. 'How long is a piece of string?' was coined as the fifth sub theme and indicated that this burden of care impacted greatly on the experiences of stress of families and especially the mothers. The loss of hopefulness and enduring uncertainty experienced by the mothers in this study caused some mothers to question how long they could maintain their level of helpfulness towards their sons.

Sub theme six described the parenting roles and concerns in regard to caring for their sons. Religious, maternal, Indigenous and agricultural belief systems underpinned parenting choices used by respondents in this study. The sense of an enduring obligation to care for a son was keenly experienced by parents in this study.

Sub theme seven in this major theme discussion highlighted the complexity of the emotional entanglement which parents experience when caring for their sons with

emergent mental health problems. This emotional burden weighed heavily on the experience of personal well being for parents in this study.

Parents find it difficult to find suitable and sufficient help for their sons in rural communities and this occurrence underpins the extreme personal burdens which are experienced by families and young men with early psychosis.

4.7 Conclusion

In this chapter the data have been analysed and the findings grouped under three major themes which represent the experiences that young men and families have had during the emergence and early phases of psychosis. The themes emerged from reading and rereading the narratives and conducting thematic analysis. In describing these themes the researcher has endeavoured to capture the experiences of accessing mental health help from a rural parent and son perspective as well as explaining the lived experiences of coping with emergent mental health problems of young rural men.

The first theme identified the ways in which help seeking occurs for families with a son experiencing early psychosis. It highlighted that families and young rural men are experienced in seeking help and providing help during the emergence of mental health problems such as psychosis. A model was developed which further describes the experiences of help seeking. The help seeking model describes the complex set of events which occur for these young men and their families in regard to help seeking within the confines of the family environment. Two sub themes emerged within the help seeking framework. The first sub theme is that young men and their families are reluctant to identify with having a mental illness. The second sub theme which emerged describes the language barrier that exists to adequately define the difficulties which young men and their family experienced.

Families in rural communities have little opportunity to develop skills in recognition of early mental health problems because there are very few locally available services in these communities. Exposure and awareness of emergent mental illness and it's appropriate treatment is not demonstrated in local communities and therefore is not part of the local conversation or dialogue when solution to vague problems are required.

The second major theme described the unpredictable behaviour that the young men experienced and the social discomfort that followed this behaviour for both the young men and their families. The third sub theme described the balancing-act that families and young men find they need to manage in regard to social stigma and social proximity. Social discomfort and unpredictable behaviours place a social management demand on young men and families. At times these demands can be overwhelming especially for the family, and result in a burden of care and responsibility which cause parents to extend their help seeking boundaries, even if the personal cost to relationships is exceedingly high.

The final major theme describes how parents struggle to find help for their son's. Finding help was very difficult for all participants in this study. Often the participants could recognise something was wrong, but selecting a helping professional was not easily achieved. Resoundingly participants did not know where to look for help. When they did find help, their confidence in professional helpers was not very high. This lack of professional help achievement at a local level placed significant burdens on families to care for their sons. 'How long is a piece of string?' was coined as the fifth sub theme, and indicated that this burden of care impacted greatly on the experiences of stress of families and especially the mothers. The sixth sub theme described the parenting roles and concerns in regard to caring for their sons. The sense of an enduring obligation to care for a son was keenly experienced by parents in this study. The final sub theme highlighted the emotional entanglement which parents experience when caring for their sons with emergent mental health problems. This emotional burden weighed heavily on the experience of personal well being for parents in this study. Parents find it difficult to find suitable and sufficient help for their sons in rural communities and this occurrence underpins the extreme personal burdens which are experienced by families and young men with early psychosis.

The following chapter will identify and discuss the major findings of this study. Conclusions about the research questions will be made and the implications for improving mental health service provision to rural populations, including recommendations for further studies will conclude this thesis.

Chapter Five

Discussion and conclusions

5.1 Introduction

This study sought to discover the barriers experienced by young rural men and their families when the young men are in the early or prodromal phases of emergent psychosis. An interpretative, phenomenological approach was utilised because the researcher deemed that this was the most appropriate methodology to explore the lived experiences of young men and their families during the emergent phases of mental illness. This methodology enabled the repeated in-depth interviewing of participants to gain rich, valuable data. Thematic analysis of the data was undertaken and three major themes emerged: *Help Seeking, Unpredictability and Social Discomforts* and *Parents Struggle to Find Help for their Sons.*

Whilst the previous chapter presented the major themes and sub themes this chapter will provide a review of the major findings and the conclusions reached about the research problem. Implications and recommendations for mental health clinical practice, mental health awareness and health promotion, and for mental health service administration and planning are discussed. This chapter concludes with recommendations for further research into this field of study.

5.2 Major findings and conclusions

5.2.1 The Early Help Seeking Model

The major finding of this study is the identification and description of the early help seeking patterns of both the young men with emergent mental health problems and their families. A seven stage process was identified and the characteristics of each of these stages were described in the previous chapter. In overview, a help seeking cascade commences with the stimulation of a trigger experienced by the young man. Sometimes the young man is able to interpret the trigger and respond to it without

assistance from anyone else. Alternatively, when he is unable to interpret and respond without assistance he would apply a trust filter strategy, whereby, he would seek another trusted person to interpret the trigger for him, and provide him with feedback such that a coping strategy is achieved which responds to the original trigger issue.

Coping might be achieved by choosing a strategy that has achieved a positive result in the past, or by trying a new strategy as suggested by the trusted other person. However, when this cascade of help seeking does not yield a positive outcome, then, the cluster of mental health risk and vulnerability escalates and mental health declines. This process is applied to helping within the context of the family for months and often years. It places a significant burden of care on the trusted helper, frequently the mother, and is a standard way of managing the day to day not quite right behaviours of a young rural male with an emergent mental health problem. When the threshold of helping in this way is surpassed, then external professional help is sought to expand the help seeking process.

5.2.2 Families have established skills as helpers

Another finding from this study suggests that families have been successfully helping their sons or significant young men for considerable periods of time. For instance, months and even years of awareness of emerging problems and helpful compensation has already occurred within the internal environment of the family prior to mental health service involvement. The family, especially parents, arrive at a point of seeking external help as skilled helpers themselves.

5.2.3 Problematic admission classification system: The client with a designated medical diagnosis

Another finding of this study is that young rural men and their families did not identify with the medical diagnoses attributed to them by health professionals. These types of diagnoses did not reflect the life problems that the young men and families were experiencing. Neither did these classifications shed any light on practical ways in

which to solve the problems that they were encountering. Medical and psychological interventions were not seen as useful by the young men or the families in this study, rather they were more inclined towards finding someone to talk to in a general counselling sense. This finding is consistent with the findings of another recent study which explored the helpfulness of early interventions from both a client and health professional perspective (Jorm et al. 2008). It is clear that health professionals hold different beliefs to that of the general population about the helpfulness of mental health services. Parents and young people have a greater level of confidence in their own abilities to help, and place a lower value on the interventions that mental health professionals may provide.

Emergent mental health problems and the onset of early psychosis are difficult to ascertain with certainty for significant periods of time. In some cases it may take years for a medical diagnosis to evolve (Edwards & McGorry 2002). State health systems require that a medical diagnosis supports an admission to either an inpatient or outpatient mental health service. This bureaucratic requirement places both medical doctors and other health care professionals in a precarious situation. Previous chapters of this thesis have highlighted the peculiar nature of emergent early psychosis, and, additionally the normal developmental changes that occur during adolescence and early adulthood. In particular, that the outward behavioural and the mental health changes of young people with emergent mental health problems are frequently difficult to define and categorise other than to say that something is not quite right. Emergent mental health problems do not lend themselves to traditional medical diagnosis such as those proposed in the bench mark diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders (DSM IV) (American Psychiatric Association 2000). They are better considered using a cluster of problems framework which is more able to capture the breath of the current situation.

5.2.4 Local rural media is a mental health promotion and awareness opportunity

This study also found local media agencies were eager communicators of mental health issues to rural populations. The sampling framework for this study included a media campaign to invite interested members of the public to participate in the study. Print, vision and radio media agencies responded to the media release which was distributed to them. Live-to-air, and pre-recorded interview opportunities arose for the researcher. The researcher was then able to highlight the study objectives in the public arena. This strategy was very successful as a participant recruitment strategy. However, the researcher also observed that this strategy had the unintended outcome of starting a wider conversation about mental health and mental health promotion awareness within the target community. Interested members of the public contacted the researcher; however, not all contacts derived from the media strategy were able to be included in the study. The researcher observed that local rural media represents a strategic opportunity to build community discourse about the mental health topic, and is a worthwhile awareness, health promotion and early identification intervention. This observation did not emerge from the actual data collected for this study, but rather during the process of commencing an active data collection phase for the study.

An interesting finding arising from the method used to recruit the study sample was that middle aged and middle income rural people responded to the media releases and media programs. The local newspapers were the most productive means for recruitment strategy. This may suggest that other sectors of the community are less likely to read the newspaper, or that middle income, middle aged people are more inclined to read their local newspaper and are more likely to have a son in the age bracket where early psychosis is most prevalent. It may also suggest that the local newspaper is a useful strategy to explore further in promoting pathways for gaining mental health help for this group.

5.2.5 Gate-keeping in rural health settings

The study also found that rural medical centres and rural hospital emergency departments were accessed by participants in this study. However, a level of dissatisfaction was reported by some respondents when accessing primary health service provision at these service entry points. These respondents reported experiences that included long waiting times, challenges in regard to negotiating an appointment with the receptionists who did not prioritise their needs as urgent, and having their physical needs met, but not having their mental health needs addressed, thereby inferring a degree of unimportance towards their mental health problems. These factors served to increase the duration of untreated psychosis, and thereby add complexity to the recovery prognosis.

Receptionists, administrative workers and medical officers/general practitioners were the first-point-of-call assisting the participants in the study. These roles represented a gate keeping function to appropriate health services for the respondents. Despite this, nurses were not reported as having a role to play by the respondents. So another finding of this study is that nurses were conspicuous by their absence in first-point-of-call engagements with young men or their families, despite the explicit discipline specific skills base that exists for mental health nurses to identify, engage and build rapport with such clients.

5.2.6 First-point-of-call and reception at the mental health service provider

The findings of this research indicate that the receptionist role has the capacity to fulfil either an early enabler or an early barrier to mental health help seeking. The moment of first point of contact with the mental health service by a consumer is a vulnerable period of time. The antecedents to a mental health service presentation may include fear of social stigmatisation, threat to reputation, long term helping, emotional vulnerability and fatigue, cognitive decline and mental health decline, including diminished judgement. The respondents in this study were deeply

concerned with the social discomforts related to contact with the health service provider.

The respondents reported that they could not convey adequately the urgent nature of their problems to a receptionist and that because the problem did not sound like a physical health risk it was perceived by the receptionist and counter transferred to the help seeker as less than urgent, and thus not expressed as a health problem in either direction. If a help seeker has emergent mental health problems, then they may not have intact insight and judgement about their own mental health problems and may conclude that they do not have a problem which warrants further health professional assistance.

This particular finding is of concern primarily because the structure which public mental health service providers utilise is guided by Mental Health Outcomes Assessment Tools (MHOAT) protocols which indicate that the reception role does not need to be filled by a person with clinical skills (NSW Department of Health 2004). Thus, an unskilled worker is the first-point-of-call for a person making mental health help-seeking enquires. This protocol presents a barrier to the early and appropriate engagement of young men with emergent psychosis is rural communities.

5.2.7 Family and clinician collaboration

This study also found that parents, especially mothers, are skilled helpers for their sons. Parent respondents were keen to work in partnership with health professionals, but reported feeling betrayed by the mental health professionals who seemed not to have a repertoire of interventions to address the problems experienced by their sons. Parents observed that little was achieved, and sometimes, that nothing further than what the parent had already done had been achieved. Parents reported experiences of not being included adequately in the treatment plans for their sons. They saw this as a threat to a full recovery for their sons and they also reported that the real problems remained unaddressed in their view.

During the often lengthy emergent phases of the mental illness experienced by respondents, the young men and/or their parents were successful in achieving some contact with various service providers, for example: school counsellor or guidance

officer. However, the confidence and the achievement of successes with these health professional contacts had been very low and dissatisfying. One parent respondent indicated that he had a *'zero confidence in so called help professionals'* following his contacts and discussions with them. Past exposure to service providers and associated poor outcomes were a barrier to seeking mental health clinical services for future help needs. Thus, parents were long standing and consistent helpers of their sons, however, they felt excluded from the recovery process at a clinical level, and they considered that clinicians did not have useful interventions to offer their sons in way of practical help. This finding is consistent with Jorm's *et.al.* (2008) finding of a public belief that clinicians do not have an array of helpful interventions to apply to young people with early psychosis.

5.2.8 Mental health awareness and health promotion in rural communities

This study found that a vocabulary problem contributes to a delay in seeking formal mental health service. This represents a significant barrier to early identification and early intervention of early psychosis for young rural men. Emergent signs and symptoms of psychosis are very difficult to ascertain and diagnose with certainty. Diagnosis of psychosis can take considerable time and ongoing assessment by mental health specialists even though they have expert knowledge of the disorder. Parents, families and the young men themselves find it considerably more difficult to comprehend and articulate the emerging problems which represent the genesis of a developing psychosis. This is primarily related to the vagueness of symptoms, the similarity to normal adolescent developmental stages, and a lack of vocabulary to identify clearly what problems are developing. The respondents in this study struggled to articulate the defining features of the problems that they encountered.

Respondents did not assimilate their lived experiential knowledge of problems with a mental health/illness language, vocabulary or framework. For many it did not occur to them that the problems they encountered were indeed related to mental illness in any way. Thus, it did not occur to them to seek mental health service provision early in their problem journey. Such help did not form logical problem solving for the respondents. This, combined with a failure of the respondents to identify where to go

to find help, contributed to a major barrier to acquiring timely and appropriate help for the young men.

The findings of this study suggest that mental health awareness and health promotion activities are insufficient within rural communities. Embedded and locally situated mental health awareness and health promotion interventionists are required in communities as a continual and trusted voice. Rural people rely on the social structures which underpin their communities, they often trust informal contact with local people who have demonstrated confidentiality and have earned an esteemed level of social proximate trust.

Respondents in this study did not have a clear idea of the types of help, and locations of help, available within their local rural community. Some respondents expressed exasperation that they did not know where to access mental health services although they had an expectation that some help should be locally available.

5.2.9 Families recognise key changes

The family unit readily recognises changes which flag the early identification of psychosis. This study has found that the families who participated in this study were equipped to recognise a range of changes in their sons, and that in fact they were skilled observers of change. Families are uniquely placed to initiate early entry into treatment pathways which can significantly reduce the duration of untreated psychosis (DUP). Some families with better functioning patterns are more likely to enter treatment significantly earlier than poorer functioning families, and gain better prognostic outcomes due to the reduced DUP time factor (Goulding et al. 2008). The findings of this study corroborate with the recommendations of Goulding *et al.* (2008) to continue to investigate the family system and family strengths and to explore dynamics which may be useful to harness in further reducing DUP, especially for young rural men.

Other recent research findings suggest that up to ten years is a possible duration of unidentified illness for rural young men with emergent psychosis (Catts 2007). The participants in this study revealed that in many cases either the parents/family and/or the young men recognised that something was not quite right with the young male ten years prior to formal mental health service admission, and in some cases, during

pre-schooling years. Thus, this study found an indication of an awareness of mental health problems, or something troubling or not quite right, for up to 20 years.

5.2.10 Summary

This section has described the major findings of this study. It has identified an important Early Help Seeking Model and recognised the skills families have as established helpers of young rural men with emergent mental health problems. Problematic service classification systems and models have been identified. Rural media has been identified as an opportunity to improve mental health promotion in rural communities.

This section has also reported on findings from the study that relate to the gate-keeping practises which interact at first-point-of-call encounters between clients and service providers. This study has found that families are keen to collaborate with mental health services to improve the mental health of young rural men. Further, this study has highlighted that families already hold valuable information and skills in regard to recognising the changes that occur during the emergent phases of early psychosis.

5.3 Implications for mental health practice and service provider planning

5.3.1 The Early Help Seeking Model

The Early Help Seeking Model effectively informs mental health clinical practice and service provision planning. Integrating this knowledge into assessment, intervention and review processes for clients and their families will add depth and rigor into the therapeutic process.

For example, understanding this model of helping which exists internally within the family setting provides the clinician with a framework to explore the therapeutic strengths which already exist within the family and presents an opportunity to enhance clinical treatment planning. This model also indicates that the trusted others

in the family are skilled and experienced helpers, which again can improve the quality of care planning especially within the community setting and when planning discharge or transfer of care.

5.3.2 Assessment of family strengths

The major implication for practice derived from the finding that parents are skilled helpers. With this background information, clinicians can strengthen their care planning by including an assessment of family helping strengths early in the episode of care. These strengths can then be incorporated usefully as part of a collaborative intervention and recovery plan. Engaging parents in this way will maintain and reinforce the Early Help Seeking Model as a baseline throughout the recovery phase and for as long as it may be needed within the family setting. The family based help seeking model may endure longer than an episode of care and therefore should be utilised, supported and encouraged by clinicians throughout current and subsequent episode/s of mental health care. Further, the Early Help Seeking Model will underpin the early identification of subsequent relapses, should they occur.

5.3.3 Families represent enduring elements of a therapeutic plan

The helping skills which families accrue are significant strengths and are likely to be useful in a therapeutic plan of care for the young man. The family are likely to be familiar with helpful strategies which have worked in the past and some of which may still yield positive results. These strengths are a resource which should be included in therapeutic care planning and in devising and implementing interventions.

A practice implication from this study, for both clinicians and mental health managers, is to prioritise family helpfulness strengths as a routine component of the comprehensive assessment process. Current mental health service assessment of adults do not comprehensively record or prompt in-depth inquiry about strengths of helping within the family, however other family strengths are acknowledged (NSW Department of Health 2004). The collection of client history and assessment data relating to family helping patterns is not highlighted within the MHOAT documentation

recording system. While some improvement is noted in the documentation tools which are available for child and adolescent families, the aspect which is not sufficiently emphasised is that of family help provision assessment. In both adult and adolescent cases, the assessment of family helping is limited to the health problems of the identified individual client, and both fail to gather sufficient information about helpful family strengths which might otherwise be reported by parents or family members and would usefully contribute to care planning. It is well known that a supportive family is a considerable asset in the recovery experiences of first episode psychosis clients (EPPIC 1998).

Thus, first identifying families' strengths, and second, integrating these family strengths into the therapeutic plan of care for young men with emergent psychosis, represents a practice shift which links usefully with the needs and roles of clients, families and clinicians. This innovative collaboration between clinicians and families is an asset in the context of the therapeutic journey of the client.

5.3.4 Implications for practice and policy. Problematic admission classification system: The client with a designated medical diagnosis.

As previously mentioned, emergent mental health problems and the onset of early psychosis are difficult to ascertain with certainty for significant periods of time. In some cases it may take years for a medical diagnosis to evolve (Edwards & McGorry 2002). State health systems require that a medical diagnosis is designated to acquire or support an admission to inpatient or outpatient mental health services. This bureaucratic requirement places both medical doctors and other health care professionals in a precarious situation because a medical diagnosis may not adequately reflect the problems being experienced by the client (Cashin 2007).

Previous chapters of this thesis have highlighted the peculiar nature of emergent early psychosis, and, additionally the normal developmental changes that occur during adolescence and early adulthood. Emergent mental health problems do not lend themselves to traditional medical diagnosis such as proposed in the bench mark diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders (DSM

IV) (American Psychiatric Association 2000). These problems are better considered using a cluster of problems framework which is more able to capture the breath of the current situation.

Nursing frameworks and diagnosis may be more suitable to explain the confronting mental health problems (Endacott et al 2006; Cashin 2007). However, there is no classification system for achieving an inpatient or outpatient admission to a mental health service which utilises a nursing diagnosis to underpin an admission to service process. Health service planners and managers are positioned to address this problem and to explore ways in which to accommodate a broader array of admission criteria which does not rely solely on a medical diagnostic classification system. Respondents in this study did not identify with having a medical diagnosis of any type of mental illness, although they did identify with having a number of problems which adversely affected their health and wellbeing. Nursing has a discipline specific knowledge base to apply to clients in this circumstance and which is currently underutilised by state health service providers. There is currently considerable global momentum within mental health nursing including the proposition of contemporary mental health nursing theoretical approaches which address problems of life and diminished wellbeing (Barker, 2009). The findings of this study supports the notion of expanded roles for mental health nurses especially as they address the practical and human problems associated with wellbeing.

5.3.5 Local rural media is a mental health promotion and awareness opportunity

Mental health practitioners should be contributing voices in the local rural mental health promotion and awareness community conversation by actively participating in local media, especially local newspaper, radio and television. Mental health service clinicians and managers should consider the influence of barriers to early participation that exist in their clinical setting and seek to reduce adverse effects of these factors. Further, mental health service clinicians and managers should be positively influential in enabling engagement and promoting early participation by clients. This may be achieved by building awareness and discourse about the early

symptoms of psychosis in the small local community, through health promotion activities. Utilising the local media is a strategic opportunity to build rural community discourse about this topic, and represents a worthwhile awareness, health promotion and early identification intervention. Harnessing the representative social capital which exists in the form of locally based media agencies will strengthen rural health and well being capacity and promote mental health community efficacy.

A further implication for practice derived from this research is that a need to build trust, rapport and confidence within the target local population exists. Establishing an improved level of confidence may achieve participation in early intervention, earlier in the morbidity profile. Any gains which reduce the duration of untreated psychosis will improve the recovery potential considerably. It is important that mental health services work to establish confidence in the small rural communities where they seek to provide service. Mental health clinicians have an especially important role in this regard, particularly at the first presentation of a new client or his parents or family.

5.3.6 Mental health nurses as first-point-of-call

Rural medical centres and rural hospital emergency departments should consider including specialist mental health nurses into staff teams with the express purpose of engaging with mental health help seekers as their first-point-of-call. Specialist mental health nurses such as credentialed mental health nurses or nurses who may participate in the federal Mental Health Nurse Initiative Scheme or work as clinical nurse specialists are ideally skilled to engage first-call clients. This initial contact needs to be timely and responsive to the immediate need expressed at the first contact with the mental health service provider, for instance a telephone call or first in-person presentation.

5.3.7 Review of MH-OAT protocols to enhance capture of early help seekers

Public mental health services are administratively underpinned by the usage of a standardised outcomes and assessment tool. This standardised system of recording mental health assessment and ongoing care together with recording occasions of various episodes of service for clients has been designed by mental health administrators, clinicians and with input from service consumers. This system is utilised in both rural and metropolitan NSW. The system is also used to record illness prevalence in populations and to support human resourcing such as staff-patient ratios. While the functionality of the system is broad, the key focus of the Mental Health Outcomes and Assessment Tools (MH-OAT) are designed to contain standardised recording of client assessment and to measure the outcomes of interventions applied to clients. It is also a tool to inform health service management regarding a range of non clinical administrative issues and trends. MH-OAT protocols inform decision making about the skills mix required within service centres. MH-OAT outcomes inform service planning and the implications of its use are far reaching.

More specifically, MH-OAT protocols indicate that the first meeting of or contact with potential new clients is not a clinical role (MH-OAT NSW Department of Health 2004). MH-OAT protocols acknowledge that triage and intake functions are both clinical roles however they occur following the initial receptionist contact in most cases (NSW Department of Health 2004). The antecedents to a health service presentation may include fear of social stigmatisation, threat to reputation, long term helping, emotional vulnerability and fatigue, cognitive decline and mental health decline, including diminished judgement. The respondents in this study were deeply concerned with the social discomforts associated with their contact with health service provider. The antecedents mentioned above are laden with clinical relevance and the very first discussion, whether by telephone or in-person, is a vital component in enabling, motivating and inviting participation in mental health service care processes.

Importantly, enabling, motivating and inviting participation are clinical skills which when used to therapeutic effect, will enhance early participation in the treatment process. Thus, an element of the clinical role is inherently embedded in the role of

first contact. The role of receptionist in rural communities is further complicated by contextual factors of rural social proximity (Boyd et al. 2008). As previously mentioned, the implication for rural mental health practice and service management includes incorporating processes so that clinicians are available at the reception point for all mental health enquiries in rural communities. Further, mental health nurses are ideally placed and skilled to integrate this function into their roles. Developing mental health nursing roles to accommodate the first presentation of a mental health help seeker will enhance and invite early identification of emergent mental health problems in rural communities.

5.3.8 Stigma and social discomforts

Literature and other recent studies underpin the well known clinical belief that childhood trauma, such as neglect, physical abuse and or sexual abuse are antecedents of adolescent and young adult mental illness including episodes of psychosis. These are adverse life events which often accompany episodes of mental illness they imply that families of young people with mental health problems contain inherent causally linked problems (Lynskey & Hall 2000; Lynskey et al*.,* 2003; Bak et al. 2005; Read et al. 2005). Thus, a factor that may nurture mental health stigma is a sense that parents or families have done something wrong which has resulted in mental illness for the young man. While there are many families where it is clear that adverse events have had a detrimental effect on the mental health of their children, there are also families where adverse events, such as, abuse have not occurred. These families have a protective strength inherent within them, yet during the initial assessment phase of intake into mental health services, some undeserved stigma may be felt by families.

Some respondents in this study were repelled by the perception that stigma, blame or fault might be attributed to them, at the parents of the young man. This belief resulted in some delay in seeking professional mental health help for some participants. It is therefore a recommendation of this study that clinicians take care to buffer this potential barrier to mental health service participation by the young man and or his family.

5.3.9 Mental health awareness and health promotion in rural communities

An implication for mental health practice arising from the findings of this study is the notion that there is a place in the clinical landscape for a locally embedded specialist mental health promotion interventionist in rural communities. The outcomes of health promotion and awareness campaigns which are designed by local mental health clinical specialists or generalist nurse specialists are likely to be well received within small rural communities (Edwards & McGorry 2002; Wilson 2007; Wilson 2008; Appendix 7). Furthermore, the social capital which exists within small rural communities which contain mental health clinicians should not be understated. This social capital community asset is bi-directional because the mental health clinician has an abundance of informal knowledge about local individuals, while, vulnerable community members are aware of local health service providers to address a range of health and wellbeing related problems (Boyd et al. 2008). For instance, a community health service centre has value to the community as a formal health service provider, but also as an informal agent of local social capital.

5.3.10 Implications for family focussed mental health care provision

Parents in this study were striving to find suitable ways to help their sons and to apply useful coping strategies to both sustain their family and support their sons. The young men in this study had supportive family networks which included their nuclear family of origin and also extended family members. This poses an opportunity for mental health professionals, to recognise the family as the identified client rather than the more traditional framework of service delivery which seeks to engage only the individual with the primary health problem to be the identified client.

Families in this study went to great lengths to help their sons. As an example of the supportive helping that families do, one family recalled their attempts to find help for their son by consulting the family solicitor. This indicates a strength of support in help seeking and problem solving, regardless of whether or not this was ideal from a mental health perspective. The families trialled a range of options to find suitable help

for their sons, demonstrating a significant strength, which could be harnessed within the intervention and recovery planning phases of focussed mental health care provision.

Providing feedback to the family about the strengths contained within the family and the reinforcement of positive attributes and decision making within the family structure would usefully add both protection and strength within recovery planning. Further, it would provide an opportunity to continue the development and acquisition of additional specific coping strategies and recovery support within the family. Feedback to families about their internal systemic strengths will further validate the helpfulness of intra-family coping strategies and is likely to engage further focussed helping. This support is especially useful in protecting a vulnerable client in the recovery phase, and also instils hopefulness in both the young man and the family (Edwards & McGorry 2002).

5.3.11 Family assessment tool and family intervention

Funding should be generated and allocated to develop an assessment tool for identified families to better understand the helping skills accrued within the family and the helpful interventions which they have applied internally prior to mental health service involvement. Funding should extend to the development of family focussed interventions which might be applied and supported by a clinician or a clinical team to further support the individual and the family with early mental health problems.

Future editions of MH-OAT (NSW Department of Health 2004) should consider adopting an assessment tool and intervention strategies which accommodate assessment of family helping strengths and which identify the family as a service recipient.

5.3.12 Specialist family interventionists

Specialist family interventionists such as mental health nurses should increasingly become valued members of mental health teams. Building family strengths and

addressing the burden of care experienced by many families was illustrated succinctly by one participant who indicated that she was *'at the end of her string'* in regard to worrying about, and caring, for her son and battling with her own psychological state to the point where she wished her son would *'just go away'* or even die. That way, she and her family would not have a continual battle in their own emotional lives and within the culture of the family.

Interventions which build on family strengths and reduce the burden of care felt by families should become a core component of recovery planning. These interventions have the potential to usefully reduce and prevent relapse, lower morbidity acuity, as well as reducing the burden on inpatient services and bed-days.

5.3.13 Implications for collaborative service provision

The families and young men in this study sought help from non-health agencies, individuals and services to address very early mental health problems. This indicates that an opportunity to widen collaborative care planning to include non-health service providers as part of the interdisciplinary helping team exists. In particular, this study revealed the utilisation of legal practitioners, school based practitioners, such as educationalists, health and welfare practitioners, and justice and correctional workers. The inclusion of legal, justice and correctional workers may add significant strength to collaborative recovery planning, where ever relevant to client needs. Some of the respondents in this study were already using these mechanisms, thus integrating recovery planning is a logical progression of this already utilised strategy. Further, early psychosis is recognised as a particular risk factor for homicides in rural New South Wales (Neilssen et al. 2007). This highlights a relationship between psychosis and homicidal risk, and as such, it is logical to suggest that collaborative interdisciplinary teams which include non health agencies are intuitive.

5.3.14 Service mapping in rural communities

Rural communities have unique services and characteristics which present opportunities for mental health resilience and protection. The capacity of communities to be mentally healthy draws from the community's inherent blend of social, and service assets represented amongst the individuals and industries which are contained within that community. An eclectic array of skills and attributes within

the community will be useful to build mental health awareness and mental health promotion. Service mapping in small communities would articulate to both the general community and service providers the types of support available within these communities. Many sources of mental health assistance may include volunteer, charitable, faith based and non government organisations. Increasingly, a range of private practitioners are available to small communities. Communication and local dissemination of these eclectic service providers will enhance uptake of help by vulnerable young people and their families. Funding for service mapping, map maintenance and public dissemination should be generated and allocated for this purpose by public health service administrators.

5.4 Recommendations for further studies

A limitation of the study is that general medical practitioners (GPs) in family/private practice were not interviewed about their views in relation to being identified as a frequent first health worker help option by families. However, this was not in the scope of this study. It is noted that the families interviewed in this study identified the GP as an intervention or help option, especially when the problems with their sons were escalating and when the parents felt that a high level of risk existed. However, is was beyond the scope of this study to explore whether GPs felt sufficiently equipped to undertake help and appropriate referral for the parents seeking help for their son. It may be that GPs are not well prepared or placed to be an initial help at the emergent phase of a pending mental illness episode (Bambling et al. 2007). This explanation has been posed by others and needs to be better understood. Evidence from the literature suggests that rural GPs self evaluate themselves as unconfident in the assessment of schizophrenia (psychosis) and the mental health problems of young people, however paradoxically they do report confidence with prescribing medication for these problems (Alexander & Fraser 2008).

It may be that other sources of help are more appropriately skilled, especially in regard to building and strengthening prevention/resilience within the young man. In this study parents however anticipate when the going gets too hard and considered that a high level of risk exists for their sons, that the GP will be able to do ‘something’. This ‘magic bullet’ approach is a last attempt to unravel a heightening

problem, yet, the disciple of medicine and specifically, general practice may not be the most effective way to intervene and problem solve sufficiently. Evidence suggests that GPs are not able to act as an early source of help for a family/son with emergent psychosis, other than to write a prescription for medication or to suggest referral (Alexander & Fraser 2008). It is unclear if referral is the most appropriate action for them to take at this point. And, it is unclear how GPs decide who to refer the client to. These are important issues to consider. GPs report that local services are not sufficiently abundant, for intake of desired referrals, within rural communities. This apparently leads GPs to utilise more complex interventions such as hospitalisation (Alexander & Fraser 2008).

It may be that rural families, in particular, hold traditional views of medical paternalistic problem solving, and are not familiar with alternative sources of local help with problem solving for escalating emergent mental health problems, such as mental health nurses and the federal government's relatively newly funded Mental Health Nurse Incentive Scheme whereby consultations are rebated by Medicare (Medicare Australia 2009). Further research needs to be undertaken to understand the public beliefs about where to access appropriate mental health help and service.

5.4.1 First point of call professional helpers

The findings of this study concluded that a range of professionals were sought by families and young men as a first-port-of-call when helping requirements had surpassed the threshold of available support within the family. Some first professional helpers included non-traditional professionals, for example, lawyers/solicitors and teachers. The researcher is aware of previous mental health clients seeking first help from other professionals such as accountants and financial counsellors. Mapping the help seeking entry points from a consumer perspective has not attracted research attention to date in rural Australian settings. Further research which identifies where families seek professional help in the first instance would contribute valuable information which would inform health promotion practice. Mental health promotion and early identification/ early intervention clinicians may be alerted to additional collaborations with non traditional professional helpers, which may enhance enabling referral to mental health professionals at an earlier phase in the duration of untreated

illness. As previously mentioned, the benefits to earlier identification and treatment of early psychosis have profound impacts on reducing the morbidity and improving prognosis for recovery.

5.4.2 Enabling early participation in mental health care

Further research should explore the enablers of early mental health service participation of young rural men and their families. This study brings to light a number of possible factors which may act to repel individuals from engaging with health service providers. Understanding barriers to health service access has attracted the attention of some other researchers in recent times (Aisbett et al. 2007; Bromley 2007). The findings of Aisbett et al. (2007) and Bromley (2007) adds further support the findings of this study. A focus for further research is to look at an alternate perspective and consider factors which invite health service participation. Such an approach has a positive and engaging focus rather than a causal and judgemental negative approach which sometimes accompanies a consideration of barriers. A discussion about barriers utilises language and vocabulary which often poses challenges. The discourse is often closed and oppositional in nature. Whereas, a discussion which invites change has more positive connotations and as a result encourages and enables client participation in health problem solving.

It is useful for mental health service providers and mental health clinicians to be conversant of the current barriers to early client participation in treatment so that plans can be made to remove any barriers to client participation in early treatment. Future research efforts should aim to identify enablers, rather than barriers, to early intervention participation by young people with emergent mental health problems and their families.

5.4.3 Limitations and methodological issues

This study is limited by lack of generalisability and a small sample size. However, there is a sense of resonance between the researcher's experience and the study findings, and the findings explain the problems faced by young men and their

families; and they are relevant to nursing and mental health clinical practice, the findings are trustworthy enough for the implications to be considered.

Many of the selected respondents nominated themselves for inclusion in this study following a media recruitment campaign. This included the publication of media releases in 'local' newspapers, screening on local television news programs in the Northern New South Wales region and live-to-air or pre-recorded talk back rural radio. Participants recruited via these mechanisms are drawn from a population of people who are interested in local media, and especially local current affairs media. People who do not have an interest in these types of media will not have been invited to participate in the study and could have been missed as the researcher further purposefully selected additional participants for the study.

The study design for a large study was not required for this study. Participants were drawn from the geographical area of northern New South Wales. Due to this limited geographical catchment area of potential participants data was only able to be captured from a discreet regional population. Respondents' responses may have influenced by the social and geographical constraints which reflect their personal experiences in relation to the study topic. Therefore, it is important to note that the findings of this research do not reflect the general population, but rather the findings are specific and report only on the experiences of the participants in this study (van Manen 1990). However, the findings of this research are able to report some common themes amongst participants which explain their experiences. This may assist in the understanding of others with similar life experiences, in particular young rural men with emergent mental health problems and their families.

5.5 Conclusion

In conclusion, the researcher believes that this study which has explored the issues that underpin the barriers to early identification and appropriate and timely treatment of emergent psychosis amongst young rural males will make a valuable contribution to the nursing and mental health literature as it has identified specific factors which influence a duration of untreated psychosis amongst young rural males. It has examined the issues that describe the early help seeking process used in families of

affected young rural males and it has identified the challenges faced by families and young people who have recognised that external professional help is required. This study has provided insight into the social discomforts and unpredictable course of emergent mental health problems which are experienced in rural communities including exposing the burden that is faced by parents who struggle to find appropriate and timely help for their sons. Finally, this study has highlighted the limitations of rural health systems to adequately communicate and invite mental health promotion, and intervention to individuals, families and the wider rural community.

It is hoped that the findings from this study will be utilised by mental health clinicians and especially mental health nurses when assessing and planning the mental health care of young rural men and their families. Additionally, mental health service managers and planners could utilise the findings when planning and reviewing mental health service provision to rural communities to assist with developing systems which engage young men and their families earlier in the emergent phase of mental health problems. In so doing, a reduction in the burden of mental illness might be achieved including a lower acuity. The duration of recovery period will be reduced if systems are able to support earlier identification and intervention of affected individuals. This is a fundamental issue if earlier mental health intervention is to be achieved for young rural men and their families.

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Appendix One

Media release/ Information flyer

What prevents young men from seeking help early with mental illness?

Rhonda Wilson, a researcher from University of New England is looking for the answers to this question.

It is difficult to detect mental illness in its very early stages. Some people describe the beginning of a psychotic episode (loss of touch with reality or confused thinking) as a time in their lives when 'something is just not quite right'. It is extremely difficult to describe the features, but people usually have a sense of something happening that they can't describe well. We also know that the sooner health workers can detect psychosis, the better the recovery from an episode is likely to be. Therefore, it would be especially useful to know more about what experiences people have in the early 'not quite right' phase of psychotic illness, as well as the factors that they think might assist them in seeking early help, and what are the key hindrances to this.

This research is especially interested in finding out more about the early psychosis experiences of young rural men.

Rhonda Wilson is looking for people who are willing to share their stories about this topic. Participants will be asked to recall their personal experiences in relation to early psychosis. There are no financial or other rewards for participants in this study. All personal information will be de-identified in any reports forthcoming from this project.

The findings of this research may assist health service providers to develop more appropriate services which are more likely to be helpful for rural people.

Rhonda Wilson is a Master of Nursing with Honours candidate, School of Health, University of New England.

For more information or to volunteer as a research participant please contact Rhonda on
Email: rwilso21@une.edu.au
Phone: 0427 037 774 or 02 6773 3952

Research Supervisor: Dr Mary Cruickshank – Senior Lecturer, School of Health, University of New England.
Email: mmacarty@une.edu.au
Phone: 02 6773 3640

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Appendix Two

Consent Form

Consent Form

Research Project: Barriers to early psychosis identification and early intervention amongst young rural males

Researcher: Rhonda Wilson (Master of Nursing Honours candidate)
School of Health, University of New England
Email: rwilso21@une.edu.au
Phone: 0427 037 774 or 02 6773 3952

Research Supervisor: Dr Mary Cruickshank – Senior Lecturer,
School of Health, University of New England
Email: mmacarty@une.edu.au
Phone: 02 6773 3640

I (the participant relative or friend) have read the information contained in the Information Sheet for Participants Relatives and Friends and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising that I may withdraw at any time. I agree that research data gathered for the study may be published, provided my name is not used. I agree to the recording of an interview.

....
Participant Date

....
Investigator Date

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Appendix Three

Information sheet for participants

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UNIVERSITY OF NEW ENGLAND

School of Health
Armidale NSW 2351 Australia
[Insert phone details here]
[Insert fax details here]
[Insert email details here]
[Insert web address here]

Information Sheet for Participants

Research Project: Barriers to early psychosis identification and early intervention amongst young rural males.

Researcher: Rhonda Wilson (Master of Nursing Honours candidate). School of Health, University of New England. Email: rwilso21@une.edu.au Phone: 0427 037 774 or 02 6773 3952

Research Supervisor: Dr Mary Cruickshank – Senior Lecturer, School of Health, University of New England. Email: mmacarty@une.edu.au Phone: 02 6773 3640.

This research project forms part of the researcher's candidature for Master of Nursing with Honours.

It is difficult to detect mental illness in its very early stages. Some people describe the beginning of a psychotic episode (loss of touch with reality or confused thinking) as a time in their lives when 'something is just not quite right'. It is extremely difficult to describe the features, but people usually have a sense of something happening that they can't describe well. We also know that the sooner health workers can detect psychosis, the better the recovery from an episode is likely to be. Therefore, it would be especially useful to know more about what experiences people have in the early 'not quite right' phase of psychotic illness, as well as the factors that they think might assist them in seeking early help, and what are the key hindrances to this.

This research is especially interested in finding out more about the early psychosis episodes of young rural men.

The findings of this research may assist health service providers to develop more appropriate services which are more likely to be helpful for rural people.

Participants are asked to recall their personal experiences in relation to early psychosis. This will take place in a one-on-one interview, or a small group, if the participant is willing. Participants are invited to nominate the venue for an interview, a place where they both feel comfortable and where their confidentially in the community will not be compromised (for example in their own home, at a community agency, outside in a park, or by telephone if desired). The interview will be recorded on a digital voice recorder, which will be erased following the transcription of the interview.

There are no financial or other rewards for participants in this study. Participants are asked to sign a consent form indicating that they consent to the interview and the storage of their personal information in a locked cabinet and by password protected computer file. All personal information will be de-identified in any reports forthcoming from this project.

The participant is free to withdraw consent and to discontinue participation in the activity at any time without prejudice.

Should recall of experiences cause any discomfort for participants, it may be useful for them to visit their regular counselor (if they have one), or a local community health centre or General Practitioner to seek further help. Alternatively the Hunter New England Health service can be contacted on 1300 669 757 to arrange mental health support if required.
This project has been approved by the Human Research Ethics Committee of the University of New England (Approval No. HE07/149, Valid to 15/08/2008).

Should you have any complaints concerning the manner in which this research is conducted, please contact the research Ethics officer at the following address:

Research Services
University of New England
Armidale NSW 2351
Telephone: 02 6773 3449 Facsimile: 02 6773 3543
Email: Ethics@pobox.une.edu.au

Thank you for your valued participation in this research project.

UNE - Achieving Regional and Global Impact

Appendix Four

Participant Selection Schedule

Project: *What are the barriers to early psychosis identification and early intervention amongst young rural males.*

Participants may contact the researcher in the first instance by phone, email or in person.

Participants will be selected according to their responses around the selection criteria below:

- Where do you live? Or what community are you from? Or where are you from?
- Are you over 18 years of age?
- Do you have any experiences of psychosis? Or, are you in a close relationship with someone who has had a recent episode of psychosis? If so, what is the nature of that relationship (eg parent, sibling, friend, partner, carer?)
- Do you have a current Mental Health Order such as a CTO (Community Treatment Order)?
- Would you be prepared to share your story/experiences with me to assist with my research?

If agreed to participate:

- Inform person that there is no reward of any kind for participating.
- That I will ask them to sign a consent form.
- That I will digitally record the interview.
- Could they provide me with a contact phone number?
- And, where and when would it be possible to meet, provide more information (information sheet for participant) and gain signed consent, and conduct a first interview, and possible subsequent interviews?

Person responsible:

Rhonda Wilson (Researcher)
School of Health, University of New England
Phone: 0427 037 774 or 02 6773 3952
Email: rwilso21@une.edu.au

Supervisor Mary Cruickshank (Supervisor)
School of Health, University of New England
Phone: 6773 3640
E-mail: mmacarty@une.edu.au

Appendix Five

Human research ethics approval

UNE
The University of
NEW ENGLAND

RESEARCH SERVICES

Armidale NSW 2351 Australia
Telephone (02) 6773 2070, Fax (02) 6773 3543

HUMAN RESEARCH ETHICS COMMITTEE

MEMORANDUM TO:	Dr M Cruickshank & Ms R Wilson School of Health

This is to advise you that the Human Research Ethics Committee has approved the following:

PROJECT TITLE:	What are the barriers to early psychosis identification and early intervention amongst young rural males?
COMMENCEMENT DATE:	15/08/2007
COMMITTEE APPROVAL No.:	HE07/149
APPROVAL VALID TO:	15/08/2008
COMMENTS:	Nil. Conditions met in full.

The Human Research Ethics Committee may grant approval for up to a maximum of three years. For approval periods greater than 12 months, researchers are required to submit an application for renewal at each twelve-month period. All researchers are required to submit a Final Report at the completion of their project. The Progress/Final Report Form is available at the following web address: http://www.une.edu.au/research-services/ethics/hrec_pages/final.report.doc

The *NHMRC National Statement on Ethical Conduct in Research Involving Humans* requires that researchers must report immediately to the Human Research Ethics Committee anything that might affect ethical acceptance of the protocol. This includes adverse reactions of participants, proposed changes in the protocol, and any other unforeseen events that might affect the continued ethical acceptability of the project.

In issuing this approval number, it is required that all data and consent forms are stored in a secure location for a minimum period of five years. These documents may be required for compliance audit processes during that time. If the location at which data and documentation are retained is changed within that five year period, the Research Ethics Officer should be advised of the new location.

Jo-Ann Sozou
Secretary

15/08/2007

Appendix Six

Hunter New England Health site specific ethics approval

HUNTER NEW ENGLAND
NSW HEALTH

3 October 2007

Mrs R. Wilson
Community Health
Locked Bag 8
ARMIDALE NSW 2350

Dear Mrs Wilson

Re: What are the barriers to early psychosis identification and early intervention amongst your rural males
HREC: HE07/149 (UNE)

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:

CAMHS Armidale (Northern Region)

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 Health

Hunter New England Human Research Ethics Committee

(Locked Bag No 1)
(New Lambton NSW 2305)
Telephone (02) 49214 950 Facsimile (02) 49214 818
Email: hnehrec@hnehealth.nsw.gov.au
Nicole.gerrand@hnehealth.nsw.gov.au
Michelle.lane@hnehealth.nsw.gov.au
http://www.hnehealth.nsw.gov.au/Human_Research_Ethics