

**School of Nursing and Midwifery**

**Young Adults' Experience of Living with a Mental Illness in Rural  
Western Australia: A Grounded Theory Approach**

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**Declaration**

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made.

Signed: \_\_\_\_\_

Date: *April 2005* .....

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## ABSTRACT

It is estimated that one in five Australians are affected by a mental disorder, and the associated burden of living with a mental illness will become one of the greatest health care issues during the next 20 years. Since the 1960s, the care of people with mental disorders has been transferred to community settings including to rural areas of Australia through the process of deinstitutionalisation. However, research on young adults living with a mental illness in rural communities is limited, and the multidimensional experience of this group of young adults has not been previously explored. This study, guided by grounded theory methodology, explored young adults' experience of living with a mental illness in rural Western Australia.

This thesis presents the findings of interviews with nine participants aged between 18 and 30 and places the findings within the context of relevant scientific literature. The constant comparative method used in grounded theory analysis identified that the basic social psychological problem experienced by all participants was "being shut out". The problem of *being shut out* consisted of two aspects: "being excluded" and "withdrawing from society". In order to manage the problem of *being shut out*, participants engaged in the basic social psychological process of "seeking normality". In *seeking normality* participants moved from a state of *being shut out* to one whereby they sought to take part in ordinary social activities taken for granted by other members of society. The process of *seeking normality* consisted of three phases: "floundering", "taking charge", and "moving forward". Phase one of the process occurred primarily in the period prior to experiencing a turning point, which changed the participants' willingness to take control of their life and to take effective steps in reducing their isolation. Participants' experience of *being shut out* was not related to the duration of their illness but to their experience of *seeking normality* and the three conditions identified as influencing that experience.

The findings, while supporting existing scientific literature, also present a new insight into young adults' experience of living with a mental illness in rural Western Australia. The findings of this study highlight the importance of health professionals' understanding young adults' experience of *being shut out* and to incorporate the increased knowledge and understanding into their clinical practice. Finally, the findings have implications on public education, healthcare services and healthcare policy in relation to young adults living with a mental illness.

## CONTENTS

Declaration .....	ii
Acknowledgements .....	iii
Abstract .....	iv
Table of contents .....	v

## PART ONE

### INTRODUCTION AND METHODOLOGY

#### CHAPTER 1: INTRODUCTION, BACKGROUND AND CONTEXT OF THE STUDY

1.1	Introduction.....	2
1.2	Definition of mental disorder.....	3
1.3	Socio-economic factors.....	4
1.4	Demographic information.....	5
1.5	Burden of disease.....	6
1.6	Deinstitutionalisation.....	7
1.7	Stigma.....	10
1.8	Need for the study and its significance.....	12
1.9	Purpose of the study.....	13
1.10	Objectives of the study.....	13
1.11	Assumptions underlying the study.....	13
1.12	Summary.....	14
1.13	Organisation of the thesis.....	14

#### CHAPTER 2: METHODOLOGY: THE GROUNDED THEORY APPROACH

2.1	Introduction.....	15
2.2	Qualitative research.....	15
2.3	The grounded theory method.....	16
2.4	Application of the grounded theory method in this study.....	18
2.5	Data collection.....	20

2.5.1	Selection and characteristics of participants.....	20
2.5.2	Research interviews.....	21
2.5.3	Field notes.....	22
2.5.4	Literature as data.....	24
2.6	Data analysis: Data coding procedures.....	24
2.6.1	Open coding.....	25
2.6.2	Theoretical coding.....	25
2.6.3	Selective coding and theoretical saturation.....	26
2.6.4	The constant comparative method of analysis.....	27
2.6.5	Theoretical memos.....	28
2.7	Researcher bias.....	29
2.8	Theoretical sensitivity.....	30
2.9	Data preparation and computer management procedures.....	31
2.10	Writing up the findings.....	31
2.11	Definition of terms.....	32
2.12	Trustworthiness, credibility and transferability.....	33
2.13	Ethical considerations.....	35
2.14	Overview of findings.....	36
2.15	Summary.....	36

## PART TWO

### THE BASIC SOCIAL PSYCHOLOGICAL PROBLEM AND PROCESS AND THE CONDITIONS INFLUENCING THE PROBLEM AND THE PROCESS

#### CHAPTER 3: THE BASIC SOCIAL PSYCHOLOGICAL PROBLEM: *BEING SHUT OUT*

3.1	An Overview.....	39
3.2	Introduction.....	40
3.3	Being excluded.....	41
3.3.1	Being excluded because of mental illness.....	41
3.3.2	Being excluded because of participant's behaviour.....	45
3.4	Withdrawing from society.....	46
3.5	Summary.....	52

**CHAPTER 4: THE BASIC SOCIAL PSYCHOLOGICAL PROCESS OF  
*SEEKING NORMALITY***

4.1	An Overview.....	54
4.2	Phase one: Floundering.....	56
4.2.1	Introduction.....	56
4.2.2	Avoidance behaviours.....	59
4.2.3	Trying to make changes.....	62
4.2.4	Summary.....	64
4.3	Phase two: Taking charge.....	65
4.3.1	Introduction.....	65
4.3.2	Turning point.....	65
4.3.2.1	Turning point brought on by a significant personal crisis.....	66
4.3.2.2	Turning point as a result of a slow accumulation of disappointments.....	67
4.3.3	Attitude change.....	68
4.3.4	Summary.....	71
4.4	Phase three: Moving forward.....	72
4.4.1	Introduction.....	72
4.4.2	Planning positive changes.....	72
4.4.3	Taking practical steps.....	75
4.4.4	Summary.....	78
4.5	Summary of the basic social psychological process.....	78

**CHAPTER 5: CONDITIONS INFLUENCING THE BASIC SOCIAL  
PSYCHOLOGICAL PROBLEM OF *BEING SHUT OUT* AND  
THE BASIC SOCIAL PSYCHOLOGICAL PROCESS OF  
*SEEKING NORMALITY***

5.1	Introduction.....	80
5.2.1	The general population's level of knowledge, understanding and exposure to mental illness.....	80
5.3	Participants' contact with health professionals and with the health care system.....	84

5.3.1	Health professionals showed respect.....	84
5.3.2	Health professionals' abuse of power.....	87
5.3.2.1	Health professionals were not interested.....	88
5.3.2.2	Health professionals were talking down to participants.....	90
5.3.2.3	Health professionals ordered participants to do things.....	91
5.3.2.4	Health professionals overstepped the mark professionally.....	92
5.3.2.5	Curbing the abuse of power.....	93
5.3.3	Inadequate health care.....	94
5.3.4	Quality of health services.....	97
5.4	Participants' level of support.....	98
5.4.1	Level of support from family members.....	98
5.4.2	Level of support from people other than family members.....	101
5.4.3	Support groups in the community.....	102
5.5	Summary.....	102

### PART THREE

#### DISCUSSION AND CONCLUSION

##### CHAPTER 6: DISCUSSION, IMPLICATIONS AND CONCLUSION

6.1	Introduction.....	105
6.2	The finding of <i>seeking normality</i> to overcome <i>being shut out</i> ....	105
6.3	Comparison of the finding in this study of <i>seeking normality</i> to overcome <i>being shut out</i> with other research findings and theories.....	109
6.3.1	A comparison of the finding in this study of <i>seeking normality</i> to overcome <i>being shut out</i> with Pickens (1999) "Living with a serious mental illness: The desire for normalcy".....	109
6.3.2	A comparison of the finding in this study of <i>seeking normality</i> to overcome <i>being shut out</i> with Smith (2000) "Recovery from a severe psychiatric disability: Findings of a qualitative study".....	110
6.3.3	A comparison of the finding in this study of <i>seeking normality</i> to overcome <i>being shut out</i> with Neale (2000) "Suicidal intent in non-fatal illicit drug overdose".....	110
6.3.4	A comparison of the finding in this study of <i>seeking normality</i> to	



	overcome <i>being shut out</i> with Hambrecht and Häfner (2000)	
	“Cannabis, vulnerability, and onset of schizophrenia” .....	112
6.3.5	A comparison of the findings in this study of <i>seeking normality</i> to overcome <i>being shut out</i> with Svedberg, Jormfeldt and Arvidsson (2003) “Patients’ conceptions of how health processes are promoted in mental health nursing” .....	112
6.3.6	A comparison of the finding in this study of <i>seeking normality</i> to overcome <i>being shut out</i> with the literature on rural mental health	113
6.3.7	A comparison of the findings in this study of <i>seeking normality</i> to overcome <i>being shut out</i> with Goffman (1968) “Stigma: Notes on the management of spoiled identity” .....	114
6.3.8	A comparison of the finding in this study of <i>seeking normality</i> to overcome <i>being shut out</i> with Link, Struening, Dohrenwend, Cullen and Shrout’s (1989) modified labelling theory approach to mental disorders.....	115
6.3.9	A comparison of the finding in this study of <i>seeking normality</i> to overcome <i>being shut out</i> with Baxter and Diehl’s (1998) model of emotional stages in recovering from the trauma of mental illness.....	117
6.3.10	A comparison of the findings in this study of <i>seeking normality</i> to overcome <i>being shut out</i> with Marris’ (1974) theory of loss and change.....	117
6.3.11	A comparison of the finding in this study of <i>seeking normality</i> to overcome <i>being shut out</i> with Parsons’ (1951) concept of the sick role.....	119
6.3.12	A comparison of the finding in this study of <i>seeking normality</i> to overcome <i>being shut out</i> with the medical model of treating people with a mental disorder.....	120
6.3.13	A comparison of the finding in this study of <i>seeking normality</i> to overcome <i>being shut out</i> with the paradigms of rehabilitation and recovery.....	123
6.3.14	Working collaboratively with consumers.....	124
6.3.15	Summary of the discussion.....	126

6.4	Implications of the findings.....	126
6.4.1	Initiatives directed towards the general population.....	126
6.4.2	Initiatives directed towards media personnel.....	128
6.4.3	Initiatives directed towards support groups in the community.....	129
6.4.4	Initiatives directed towards government policy planners.....	129
6.4.5	Initiatives directed towards health professionals.....	131
6.4.6	Initiatives directed towards nurses.....	133
6.5	Limitations of the study.....	135
6.6	Further research.....	135
6.7	Concluding statement.....	136
<b>REFERENCES.....</b>		<b>137</b>

### LIST OF FIGURES

Figure 1	The basic social psychological process: <i>Being shut out</i> .....	40
Figure 2	The basic social psychological process: <i>Seeking normality</i> .....	57
Figure 3	Conditions influencing the basic social psychological problem of <i>being shut out</i> and the basic social psychological process of <i>seeking normality</i> .....	108

### APPENDICES

Appendix A	Diagnostic and statistical manual of the American Psychiatric Association.....	153
Appendix B	Permission to use the diagnostic and statistical manual of the American Psychiatric Association.....	166
Appendix C	Letter to organisations and health professionals.....	168
Appendix D	Information sheet for participants.....	169
Appendix E	Ethics approval to conduct the study.....	171
Appendix F	Consent form.....	172
Appendix G	Semi structured interview guide.....	173

**PART ONE**

**CHAPTER 1: INTRODUCTION, BACKGROUND AND CONTEXT OF THE  
STUDY**

**CHAPTER 2: METHODOLOGY: THE GROUNDED THEORY APPROACH**

## CHAPTER 1

### INTRODUCTION, BACKGROUND AND CONTEXT OF THE STUDY

#### 1.1: Introduction

Historically, people living in Western society who had a mental disorder suffered ill treatment (Herman & Green, 1991) and social exclusion (Morrall & Hazelton, 2000) to the point where they did not feel part of humanity (Glass, 1989). Before the 19<sup>th</sup> century most people with a mental disorder were left to fend for themselves, leading to a life of destitution (Herman & Green, 1991). According to these authors, in the 19<sup>th</sup> century treatment methods changed and tens of thousands of people with a mental disorder were moved into asylums built on the outskirts of cities. The advancement in pharmacological treatment and a philosophical paradigm shift in the care of people with a mental disorder enabled governments and health care professionals to close the once prized asylums and to move patients into the community (Herman & Green, 1991).

Despite the fact that most people with a mental disorder now live in the community they largely remained hidden (Groom, Hickie & Davenport, 2003) and silent for fear of experiencing discrimination (Stroman, 2003). Until recently, people with a mental disorder who spoke out were often ignored or regarded with condescension (Porter, 1987). According to Porter (1987), history has been written in the main from the perspective of the establishment who considered “what the mad said was no better than meaningless babble” (p. 2). The perspective of people who have a mental disorder has only recently been recognised as valuable, and in Australia this has been reflected in the National Mental Health Policy documents (Australian Health Ministers, 1992, 1998, 2003) and in the Mental Health Statement of Rights and Responsibilities (Commonwealth of Australia, 1995).

Young adults are an important subgroup of mental health consumers as the onset of mental disorders regularly occurs in the late teens or early adulthood. What life is like for young adults, aged between 18 and 30, living with a mental illness is the focus of this study and the findings will make a significant contribution to the understanding of the experience of living with a mental illness in the 21<sup>st</sup> century. This chapter will explore the background of the study and provide definitions of mental health terms that will be presented in the thesis. In addition, the chapter will

detail the need, significance, purpose, objectives and assumptions made by the researcher prior to commencement of the study.

## **1.2: Definition of mental disorder**

According to the World Health Organisation (2001) mental disorders are defined as conditions affecting mental functioning “characterised by alterations in thinking, mood (emotions) or behaviour associated with personal distress and/or impaired functioning” (p.21). The Australian Institute of Health and Welfare (1998) stated that mental health disorders “refer to the spectrum of cognitive, emotional, and behavioural disorders that interfere with the lives and productivity of people” (introduction, p. xi).

A person is diagnosed with a mental disorder by conventions used in the medical model of psychiatry. These conventions dictate Western societies’ understanding of mental disorders. Sadock and Sadock (2003) explained that a person was diagnosed with a mental disorder when their presenting signs and symptoms were compared with the diagnostic criteria published in one of the two classification systems, the DSM-IV-TR (Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision) or the IDC-10 (International Statistical Classification of Diseases and Related Health Problems, 10<sup>th</sup> edition). Specific clinical manifestations must be present for a diagnosis to be made. Where appropriate, associated features can also be included such as age of onset, gender related factors, prevalence and incidence, course, complications and familiar pattern. However, theories of causation and treatment methods are not covered in the two classification systems. Both classification systems are used throughout the world.

Sadock and Sadock (2003) stated that in the DSM-IV-TR mental disorders are classified using five axes. Psychiatric disorders are grouped along Axis I, personality disorders and mental retardation along Axis II, and general medical conditions associated with psychiatric disorders along Axis III. Axis IV assesses psychosocial and environmental problems such as stress associated with the disorder and Axis V deals with the level of social, occupational and psychological functioning of the person during the last 12 months.

Both the terms mental disorder and mental illness are used throughout this thesis. Therefore, it is necessary to clarify their use within this context. Disorders are disturbances of body systems or mental functions (Meadows, 2001), and mental

disorders are referred to in Axis I in the DSM-IV-TR. According to Meadows (2001), the term disorder implies that the cause has not been identified, in contrast to the term disease where a specific pathogen or biochemical or physiological dysfunction has been found. The term illness assessed the consequences of the disorder on the affected person in terms of impairment, disability and functioning as identified on Axes IV and V of the DSM-IV-TR. Therefore, within the context of this thesis, the focus is on describing the impact of living with a mental disorder in terms of impairment, disability and functioning. When discussing the context in which people with a mental disorder live, several key factors have been identified that impact on that experience.

### **1.3: Socio-economic factors**

Socio-economic factors influence a person's ability to live with a mental disorder (Satcher, 1999). The World Health Organisation (2001) noted that poverty, unemployment, the absence of supportive social networks and domestic violence were associated with higher levels of mental health problems. Other factors were urbanisation, migration, lack of transport and communication, low levels of education, deprivation, homelessness, sex discrimination, overwork and sexual violence. In addition, they identified that isolation and limited educational and economic opportunities adversely influenced the mental health of rural communities.

Poverty was referred to as having not only a lack of money and material possessions but as having insufficient means, which included the lack of social and educational resources (World Health Organisation, 2001). The World Health Organisation (2001) pointed to two explanations as to why poverty was associated with a higher prevalence of mental disorders. The causal mechanism stated that poverty contributed to mental health problems, particularly anxiety and depression (World Health Organisation, 2001). The drift mechanism purported that people who had a mental disorder, specifically a psychotic disorder such as schizophrenia, had lower levels of social functioning and employment and, therefore, moved into a state of poverty due to their diminished life opportunities (Kinderman & Cooke, 2000). The World Health Organisation (2001) also reported that the course of mental disorders was prolonged for people living in poor socio-economic circumstances as they faced greater barriers when accessing treatment. In summary, socio-economic

factors affected the prevalence and course of mental disorders, and young adults were particularly vulnerable to these influences.

#### **1.4: Demographic information**

Quantitative measurements of the occurrence of mental disorders give an impression of the immense size of the problem. Extensive surveys have been carried out in the 1990s (Australian Bureau of Statistics, 1998; The World Health Organisation, 2001) measuring the number of people with a mental disorder by using prevalence, defined by the Australian Bureau of Statistics (1998) as the number of cases present in a given time, as an indicator. Comparing the prevalence of mental disorders between different studies was difficult (Australian Institute of Health and Welfare, 1998) because different tools and time frames were used. Large-scale community based surveys were often the preferred measuring tools and have been deemed more reliable because they were carried out independently from whether people received treatment (Klerman, & Weissman, 1989). For example, in Western Australia a survey found that only half of the population who admitted to mental health problems received treatment (Burgess et al., 2002).

Both the World Health Organisation (2001) and the Australian Bureau of Statistics (1998) used the Composite International Diagnostic Interview (CIDI) as a tool to measure prevalence. The CIDI consists of a comprehensive interview for adults assessing the symptoms of mental disorders and their impact on daily life according to the criteria of the IDC-10 (Australian Bureau of Statistics, 1998). The World Health Organization (2001) identified that worldwide 450 million people have a mental disorder by measuring the prevalence of depressive disorders, schizophrenia, substance use disorders, dementias and epilepsy. The point prevalence was 10 % and the lifetime prevalence was 25 % of adults.

In Australia, the Australian Bureau of Statistics (1998) measured the 12-month prevalence of anxiety, affective and substance related disorders in adults in a household survey using a modified CIDI and found that 18 % of the population in all Australian states, with the exception of Western Australia, had a mental disorder. In Western Australia the prevalence was 24 %. Young adults aged 18 to 24 years had the highest prevalence at 27 % Australia-wide, excluding Victoria and Western Australia (Australian Bureau of Statistics, 1998). In Western Australia the prevalence of this group was 34 % (Australian Bureau of Statistics, 1998).

Therefore, it is important to fully understand the experience of young adults living with a mental disorder. Australia-wide, psychotic conditions such as schizophrenia were classed as low prevalence mental disorders and accounted for 0.47 % of adults who were in contact with mental health services in a one-month period (Jablensky et al., 1999).

A high prevalence rate of mental disorders was also present in the general adult population in rural areas of Australia. In rural South Australia, the prevalence was 26.4 % (Clayer, Bookless, Air & McFarlane, 1995) and in rural Western Australia the rate was consistently at 24 % whether it was measured in the Eastern Wheatbelt (Day, Kane & Roberts, 2000), in Bunbury (Aoun, Underwood & Rouse, 1997) or in the Midwest (Burgess et al., 2002, using data from the Australian Bureau of Statistics, 1998).

The prevalence of suicide in young people was also relevant in the context of this study because up to 90 % of young people who committed suicide had evidence of a mental disorder or serious mental health problems (Mental Health Branch, 1997). Australia-wide, suicide rates were especially high in young males between the ages of 15 and 24, with above 24 per 100 000. The rate for young females was between three and six per 100 000 (Mental Health Branch, 1997). In rural and remote areas with a population of less than 25 000 the suicide rate among young males was even higher at between 42 and 49.7 per 100 000 population (Mental Health Branch, 1997). In Western Australia, according to the unpublished Coroner's Database (2004, cited by the Ministerial Council for Suicide Prevention, 2004) the suicide rates for males, aged 25 to 34, was the highest of any age group at 42.3 per 100 000 in the year 2000. In summary, the prevalence of mental disorders provided an indication of the size of problem but did not reveal the impact of the disability associated with mental disorders on affected individuals.

### **1.5: Burden of disease**

The burden of disease measures the years of life lost due to disability (Mathers, Vos & Stephenson, 1999). These authors explained how this is calculated:

The loss of healthy life due to non-fatal conditions requires estimation of the incidence of the health condition (disease or injury) in a specified time period. For each new case, the number of years of healthy life lost is obtained by multiplying the average duration of the condition (to remission



or death) by a severity weight that measures the loss of healthy life using an average health state weight (p. 14).

The Australian Health Ministers (1998, citing the World Health Organization and the World Bank) stated that the disease burden due to mental disorders was almost 11 % worldwide. This is estimated to rise to 15 % by 2020. In Australia, the years lost to disability for mental disorders were the leading cause of overall burden for all major disease groups with about 320 000 years lost due to mental disorders (Mathers et al., 1999). The years lost to disability due to mental disorders in young adults, aged 15 to 24, were the highest of any age group at nearly 60 % for all disease groups (Mathers et al., 1999). The importance of the burden of disease is reflected in the cost of care for people with a mental disorder. The Global Burden of Disease Study (Murray & Lopez, 1996) equated the level of disability of living with schizophrenia and depression to the disability of someone with quadriplegia and paraplegia respectively. Andrews, Issakidis, Sanderson, Corry and Lapsley (2004) put the cost of the disease management program in Australia dealing with anxiety and depression at \$15 000 to \$ 20 000 per year and that of schizophrenia at \$ 200 000 per year. Fifteen to 25 % of all days in hospital were due to people with a mental disorder (Commonwealth of Australia, 1995). As the incidence of mental disorders in young people is increasing, the associated burden of direct treatment, disability and unemployment is also rising (Groom et al., 2003).

The high cost of looking after people with mental disorders had already been recognised by governments in the 1960s (Mechanic & Rocheford, 1990). Governments addressed this growing problem through the process of deinstitutionalisation. This process led to the number of inpatient beds being dramatically reduced and the movement of people once housed in mental institutions into the community.

### **1.6: Deinstitutionalisation**

Nothing has changed the environment for people living with a mental disorder more in the last 50 years than the process of deinstitutionalisation, and it has been described as the “single most important issue” concerning the service delivery for people with a mental disorder (Mechanic & Rocheford, 1990, citing Rich, 1986, p. 307). Although young adults with a mental disorder have not gone through the process of deinstitutionalisation they are experiencing the outcomes of the changes

resulting from this process. Deinstitutionalisation was achieved by reducing the number of inpatients in psychiatric hospitals with the discharge of large numbers of patients into the community (Sadock & Sadock, 2003) along with fewer admissions and readmissions (Stroman, 2003) and shorter length of stay (Coffey, 1994). In Australia, the inpatient population of psychiatric hospitals was reduced by 86 % between the 1960s and 1992 (Burdekin, Guilfoyle & Hall, 1993). Globally, as a result of deinstitutionalisation, the provision of mental health care in the least restrictive environment has continued to expand (Mechanic, 1987). Modern community mental health care, supported by legislature, aims to maintain the consumer in their community by providing treatment, rehabilitation, and support services at a local level.

Deinstitutionalisation was carried out for ideological, judicial and economic reasons (Mechanic & Rocheford, 1990). Ideological reasons were based on the belief that institutions were detrimental to the well being of patients because they fostered dependency, a sense of hopelessness and helplessness and produced abnormal behaviour in their occupants (Goffman, 1961). Living in the community was seen as a way for people with a mental disorder to live a more normal life and maintain connections with society (Newton, Rosen, Tennant & Hobbs, 2001). Morrall and Hazelton (2000) found that instead of achieving social integration, people with a mental disorder have met "profound social indifference" (p. 92) in the community.

Judicial reasons for deinstitutionalisation were based on the human rights movement in the 1960s, which demanded increased recognition of the rights of people with a mental disorder (Herman & Green, 1991; Mechanic & Rocheford, 1990). In Australia, the Burdekin Report (Burdekin et al., 1993), which found that the human rights of people with a mental disorder were highly inadequate, and a series of policy documents released by the Australian government (Australian Health Ministers, 1992, 1998, 2003; Commonwealth of Australia, 1995) sought to address the lack of human rights of people with a mental disorder. Neither the Burdekin Report nor the policy documents included a section specifically concerned with young adults, aged 18 to 30. The judicial reasons for deinstitutionalisation found approval from mental health consumers who stated that they enjoyed the freedom of living in the community where they could make their own decisions and have some control over their lives (Newton et al., 2001). However, research by McFadyen and

Farrington (1996) established that “people with severe mental illness are continuing to be disenfranchised ... and [are] abandoned under the banner of civil liberty” (p. 927).

Economic reasons for deinstitutionalisation were based on the high cost of psychiatric hospital care, which could be reduced by transferring care into the community, and hence onto the family (Wynaden, 2002). This aim was achieved in Australia, and it was estimated that community care was half to one third the cost of hospital care (Lapsley et al., 2000). However, the implementation of community care was viewed as a failure because not enough resources were allocated to meet the need for community-based services (Groom et al., 2003). Australia is only using seven percent of its health budget on mental health services whereas other developed countries use 10 to 14 % (Groom et al., 2003). Deinstitutionalisation without adequate community care resulted in trans-institutionalisation where people with a mental disorder have been transferred from the psychiatric hospital to other institutions such as nursing homes, general hospitals, hostels, shelters for the homeless and prisons (Mechanic & Rocheford, 1990; Sadock & Sadock, 2003), or to the care of their families who were not sufficiently supported to provide this care (Wynaden, 2002).

To counter the disadvantages of deinstitutionalisation, the Australian government (1992, 1998, 2003) devised three National Mental Health Plans to enhance mental health care for the Australian community. These plans sought to include consumers and their carers in decision-making, to increase the quality of community-based care and to promote mental health and prevent mental illness (Groom et al., 2003). These authors described the objectives of these plans as world leading but found that the implementation of community care fell short because the reform process was not fast enough and insufficient resources were allocated to the process. The lack of resources remains a problem today (Department of Health, Office of Mental Health, 2004a). The Western Australian Health Department has responded to this lack of resources by increasing the spending on mental health to 9 % of the total health budget, which will provide extra funding for emergency services and community supported accommodation, an increase in the number of inpatient beds for people with severe mental illness and the employment of an extra 425 mental health staff (Department of Health, Office of Mental Health, 2004b).

Despite the large number of young adults with mental disorders now living in the community and the burden they carry they are not vociferous about demanding improved services. One reason for their continued marginalisation is the stigma associated with having a mental illness.

### 1.7: Stigma

Mental illness is seen as one of the most stigmatised conditions worldwide (Johnson, 2001) and Fink and Tasman (1992) called stigma “the most powerful anti-therapeutic forces that mentally ill individuals face” (introduction, p. xi). Goffman (1989) defined stigma as “an attribute that is deeply discrediting” (p. 13) and as an “undesirable differentness from what is anticipated” (p. 15). Johns et al. (1984) described the process of stigmatisation as firstly identifying someone who possessed a mark or something that deviated from the norm, and secondly, linking this mark with attributes that were singled out as discrediting by other people. Stigma was called “a token of disgrace, a taint, a blemish, a blot on one’s good name” (Siantz, 1993, p. 10), and its hallmark was the “devaluation and dehumanisation by others” (Crocker & Quinn, 2000, p. 153). Stigma was so powerful that the original discrediting mark might not even exist anymore as the label by itself or association with the label was sufficient to produce a negative reaction in the public (Farina, Fisher & Fisher, 1992).

People with a mental disorder were discriminated against as a consequence of stigma (Goffman, 1968). Stroman (2003) defined discrimination as unequal treatment. He distinguished between interpersonal discrimination and institutional discrimination. Interpersonal discrimination occurred when individuals acted by themselves and did not represent an organisation. The public saw people with a mental disorder as not quite human and inferior to unaffected people (Goffman, 1968). People with a mental disorder were disliked, devalued and rejected (Farina et al., 1992) and perceived to be dangerous (Penn, Kommana, Mansfield & Link, 1999). Satcher (1999) reported that stigma produced low self-esteem, isolation and hopelessness in people with a mental disorder. As a result of stigma these people felt compelled to keep their mental illness hidden (Heffern, 1993). Therefore they were reluctant to seek treatment (Phelan, Link, Stueve & Pescosolido, 2000) and reduced their social interaction with other people (Johns et al., 1984). Institutional discrimination led to unequal treatment with regards to employment, housing, health

care and access to support services (Stroman, 2003). Stigma also reduced government funding for services and limited research (Heffern, 1993) and, therefore, people with a mental disorder were disadvantaged in this area as well.

The stigma associated with mental illness was reflected in the media (Stroman, 2003) due to the media's misrepresentation of mental illness (Nairn, 2003). This misrepresentation had a negative effect on the state of mind of people with a mental disorder, producing depression and withdrawal (Ferriman, 2000). Nairn (2003) found in his interviews with people who had a mental disorder that they were frustrated at being portrayed as someone to be feared and discriminated against rather than as someone who could cope with living with a mental disorder, which they expressed as: "People never see us living well" (p. 3).

Some authors maintained that the media had a pervasive and influential role in shaping public opinion (Williams & Taylor, 1995) by linking violence and mental illness (Cutcliffe & Hannigan, 2001). Whereas other authors found that the negative public attitude towards mental illness predated media coverage and that the media only reinforced existing public perceptions (Bhugra, 1989). Anderson (2003) stated that the media focussed on the negative aspects of mental illness because they wanted to entertain their audience and that, in fact, the audience became the "co-creators" (citing Barthes, 1972, p. 304) of published stories. Anderson wrote that "the notion that film representations and newspaper reporting of mental illness were responsible for the formation of public opinion is a myth" (p. 305).

Sartorius (1998) stated that stigma had become the greatest barrier for people with a mental disorder to living a normal life in the community. Moreover, Maher (2000) maintained that people with a mental disorder would not be integrated into society until stigma was reduced. Attempts at changing public perception of mental illness have been made. In Australia, advertisements with simple and positive images have been used to improve the image of people with a mental disorder such as the Community Awareness Program, which sought to increase the public's knowledge through advertisements (Epstein & Olsen, 2001). Other methods used to decrease stigma included education programmes conducted by support groups such as the Friends of the Mentally Ill and Carers' Association, and the Schizophrenia Fellowship (Epstein & Olsen, 2001). People with a mental disorder directly contacting the public were also found to have a positive effect (Epstein & Olsen, 2001). Phelan et al. (2000) found that although stigma against people with less

serious mental disorders had decreased in the last 50 years, fear and stigma against people with severe mental disorders had increased. They concluded that “the most serious mental illnesses will continue to be complicated by the injurious effects of stigma and rejection” (p. 205). In summary, the impact of stigma and its adverse consequences are complex issues and have been found to be important factors in the lives of people with a mental disorder.

### **1.8: Need for the study and its significance**

Young adults have been identified as a group with a high prevalence of mental disorders (Kaplan & Sadock, 1998) especially in some rural areas as evidenced by the high suicide rate (Mental Health Branch, 1997) as 90% of people who commit suicide have a psychological disorder (Barlow & Durand, 2001, citing Black & Winokur, 1990; Brent & Kolko, 1990; Conwell et al., 1996; Garland & Zigler, 1993). Young adults are also at risk because many are confused and unsure what is happening to them when the illness begins. Furthermore, the burden of disease associated with mental disorders was highest in this age group (Mathers et al., 1999). Quantitative literature on people living with a mental illness in rural areas has mainly focused on demographics (Clayer et al, 1995; Day, Kane & Roberts, 2000) and on factors affecting service delivery (Aoun, Underwood & Rouse, 1996; Malcolm, 2002). Some qualitative studies have been conducted but these studies have been on adult mental health consumers living in urban areas (Chadwick, 1997; Chernomas, Clarke & Chisholm, 2000; Humberstone, 2002; Pickens, 1999; Sayre, 2000). The only qualitative study including the viewpoint of nine young adults with psychosis aged 18 to 30 living in a rural area was a Doctoral Thesis by McCann in 1999 (McCann & Clark, 2004). This study also interviewed 24 mental health nurses and the findings predominately portrayed their views. McCann published his research in three articles exploring how community mental health nurses could uncover hope in young adults with schizophrenia (McCann, 2002), how community mental health nurses developed interpersonal relationships (McCann & Baker, 2001) and advanced self-determination in their clients (McCann & Clark, 2004). Fuller, Edwards, Procter and Moss (2000) highlighted the lack of research concerning young adults living with a mental illness in a rural area, and the National Action Plan for Promotion, Prevention and Early Intervention for Mental Health (Commonwealth

Department of Health and Aged Care, 2000) recommended that further research is needed to understand the impact of mental illness on this consumer group.

The findings of this study will provide a framework for health professionals and policy makers to work more effectively with young adults with a mental illness and will lead to the development of best practice standards in community mental health nursing. In addition, the findings provide young adults living with a mental illness and the general population with an increased understanding of how mental illness impacts on these people's lives.

### **1.9: Purpose of the study**

The purpose of this study was to obtain a multi-dimensional insight into young adults' experience of living with a mental illness in rural Western Australia. The grounded theory method was chosen because it was viewed as the most appropriate methodology for exploring and explaining the phenomenon under study. The use of the grounded theory method will be further discussed in chapter two of this thesis.

### **1.10: Objectives of the study**

In order to achieve the above purpose the objectives of this study were, in the context of a rural West Australian region and from the young adult's perspective, to:

1. Explore and describe young adults' experience of living with a mental illness in rural Western Australia;
2. Identify factors that impact on that experience; and
3. Place the findings in the context of current scientific literature.

### **1.11: Assumptions underlying the study**

Prior to commencing this study the researcher held several assumptions about young people living with a mental illness. These were:

1. Young adults are confused about what is happening to them and do not know how to handle living with a mental illness.
2. Young adults living with a mental illness experience economical, psychological, physical and social disadvantages.
3. An increased understanding of what it is like to live with a mental illness has the potential to enhance outcomes for mental health consumers, carers and services.

### **1.12: Summary**

This chapter outlined the socio-economic and demographic factors relating to young adults living with a mental illness and described the impact of deinstitutionalisation and stigma on their lives. Young adults with a mental illness living in a rural area have been recognised as important because of the high prevalence of mental disorders occurring in this group. It was timely, therefore, that the multidimensional experience of young adults living with a mental illness in a rural area was explored and documented.

### **1.13: Organisation of the thesis**

Part one of this thesis consists of two chapters, with chapter one containing the introduction and background as well as the context, purpose, objectives and justification for the study. Chapter two describes the use of the grounded theory method and the application of this method in this study. The chapter concludes with an overview of the findings.

Part two of the thesis is comprised of three chapters. Chapter three outlines the basic social psychological problem of *being shut out* as experienced by participants. Chapter four describes the basic social psychological process of *seeking normality*, which the participants engaged in to manage their experience of *being shut out*. The conditions influencing the basic social psychological problem and the basic social psychological process are presented in chapter five. Part three of the thesis focuses on the discussion, implications and concluding statement of the thesis.



## CHAPTER 2

### METHODOLOGY: THE GROUNDED THEORY APPROACH

#### 2.1: Introduction

Chapter two describes the methodology used to investigate young adults' experience of living with a mental illness in rural Western Australia. It details the reason for using qualitative research, in particular the grounded theory method as espoused by Glaser and Strauss (1967). The grounded theory method was the chosen framework for data analysis and the methodological steps outlined in this thesis are based on that framework. The chapter also contains a description of participants, ethical considerations, data collection and storage methods along with procedures used to ensure trustworthiness, credibility, and transferability of the findings. The chapter concludes with an overview of the study's major findings.

#### 2.2: Qualitative research

Modern nursing care is based on scientific principles arrived at through research that enables nurses to provide effective and efficient health care outcomes for clients (Beanland, Schneider, LoBiondo-Wood & Haber, 1999). Mental health nursing in particular is concerned with "help [ing] consumers to manage mental health problems within the reality of their life situation" (Hazelton, 1999, p. 33). This care is based on the realisation that consumers are the experts in their own lives and, therefore know "what makes them sick and what makes them well" (Victorian Mental Illness Awareness Council, 1997, p. 18). Honey (1999), in her study on consumer participation in mental health services, ascertained that:

Participants overwhelmingly agreed that consumers have a unique perspective because of their first-hand experience of mental illness and mental health services. That is what makes consumer input so critical .... Because of this unique perspective, consumers' ideas and opinions may be very different from those of other interested parties. (p. 272)

Qualitative research allows consumers' concerns to be fully documented and understood and, therefore, health professionals are able to respond to these concerns effectively (Polit, Beck & Hungler, 2001). Strauss and Corbin (1990) defined qualitative research as any kind of research not based on the use of statistical methods and analysis. Tanenbaum (2003) asserted that:

Qualitative research ... does not count things so much as interpret them. That is, it searches out the meanings of things, especially to the people who experience them ... seeking a deeper and more complex truth about how patients ... make sense of illness. (p. 291)

Strauss (1987) pointed to the following characteristics of qualitative research: a) complexity, b) the use of experiential data, and c) induction, deduction and verification. He explained that qualitative research was able to grasp and explain the complexity of real life situations. Complexity was evident when the examination of data revealed a multitude of concepts and what "lies in, behind, and beyond those data" (p. 10). In order to analyse this complexity, data had to be interpreted whilst being collected and successively more abstract interpretations had to be produced. Using experiential data, defined as the researcher's personal experience and prior knowledge of the area of study, was also important. The use of experiential data prevented the findings from being implausible, useless and irrelevant.

According to Strauss (1987), qualitative research, along with other scientific research, used the process of conception, elaboration and checking out the findings. Theoretical findings were arrived at through the process of discovering new phenomena, also called induction. Elaboration or deduction involved seeking out implications; and checking out the findings was achieved by going back to the data or collecting new data to verify the findings.

Qualitative methodology was the chosen method in this research because the phenomenon being studied was complex, benefited from the use of experiential data and required the process of induction, deduction and verification. The grounded theory method was chosen because it fulfilled the above criteria, and the researcher was able to obtain an insight into young adults' complex experience of living with a mental illness in a rural area, a phenomenon that had not been explored in depth previously from a qualitative perspective.

### **2.3: The grounded theory method**

Glaser and Strauss first described the grounded theory method in 1967 in their book *The Discovery of Grounded Theory*. Grounded theory has its roots in the social sciences (Chenitz & Swanson, 1990), particularly in the "interpretive tradition of symbolic interactionism" (Benoliel, 1996, p. 406). The term symbolic interactionism was coined by Blumer (1969) and was based on the work of Mead

(Meltzer, Petras & Reynolds, 1975). It is now a recognised method of studying “human group life and human conduct” (Blumer, 1969, p.1). According to Blumer (1969), the term symbolic interactionism signified that human beings attached meanings not only to objects in their daily life but also to their social interaction with other people. Individuals interpreted these meanings and shaped their behaviour on the basis of this interpretation. Blumer (1969) described human behaviour as not merely a product of external factors such as stimuli, social position or cultural influences but as being initiated by “the meaning that things have for human beings” (p. 3). He emphasised that “the role of meaning in the formation of behaviour ... [is] central in their own right” (p.3). According to Glaser (1992), the grounded theory method took the interpretation of meaning in social interaction on board and studied “the interrelationship between meaning in the perception of the subjects and their action” (p. 16).

Stern (1994) pointed out that the grounded theory method was especially useful when no existing theories were available or when a “fresh perspective in a familiar situation” (p. 116) was needed. Charmaz (2000) added that the grounded theory method was particularly suited to understanding processes, as “the grounded theory quest for the study of basic social processes fosters the identification of connections between events” (p. 522). These processes could then be studied “as they vary under different conditions” (Mullen & Reynolds, 1994, p. 128). Another advantage of the grounded theory method was that “strategies ... guide the researcher step by step through an analytic process” (Charmaz, 2000, p. 522). Strauss (1987) explained that the grounded theory method differed from other qualitative methods in the “style of doing qualitative analysis that includes a number of distinct features ... and [in] certain methodological guidelines ... to ensure conceptual development and density” (p. 5). Stern (1980, cited in Streubert & Carpenter, 1999) summed up the unique characteristics of the grounded theory method:

1. The conceptual framework of grounded theory is generated from the data rather than previous studies.
2. The researcher attempts to discover dominant processes in the social scene rather than describe the unit under investigation.
3. The researcher compares [each piece of] ... data with all other data.
4. The researcher may modify data collection according to the advancing theory; that is, the researcher drops false leads or asks more penetrating questions as needed. (p. 102)

This last characteristic of the grounded theory method meant that data collection methods were determined by data analysis and these methods varied according to the outcomes of the analysis. Stern (1980, cited in Streubert & Carpenter, 1999) added that another difference between the grounded theory method and other qualitative methods was that: "The investigator examines data as they arrive, and begins to code, categorize, conceptualise, and write the first few thoughts concerning the research report almost from the beginning of the study" (p. 102).

Nurse researchers have used the grounded theory method since its first publication in the 1960s, but its application in nursing research became more popular in the 1980s (Benoliel, 1996). May (1996) claimed that in the 1990s the application of the grounded theory method was widespread and had become important to the development of a theoretical base for nursing practice. According to Hutchison (1986) the grounded theory method offered researchers the "freedom to intelligently and imaginatively explore issues and concerns with social psychological consequences ... relevant to human behaviour" (p. 129). The analysis of these issues and the theoretical implications could then become a useful to guide clinical practice (Hutchison, 1986).

#### **2.4: Application of the grounded theory method in this study**

Glaser and Strauss' original grounded theory method diverged into two streams after the publication of the *Basics of Qualitative Research* by Strauss and Corbin, a nurse researcher, in 1990. Following this, Glaser (1992) accused Strauss and Corbin of changing the grounded theory method to the extent that it could not come under the banner of grounded theory any more. Glaser (1992) pointed out that Strauss and Corbin's (1990) explanation of grounded theory was "forced, preconceived [and] full of conceptual description" (p.3). Melia (1996) added that she also found Strauss and Corbin's work formulaic, with too many rules and procedures and that the "technical tail is beginning to wag the theoretical dog" (p. 376). Glaser (1992) stressed that the process of data analysis and the emergence of theoretical findings was largely creative and should not be restricted by too many rules. In contrast, Strauss maintained that some researchers were struggling to understand the grounded theory method and the techniques needed clarification (Strauss & Corbin, 1998). Over some years Strauss developed guidelines that

differed from the original ones set out by Glaser and Strauss (Strauss & Corbin, 1998).

While the researcher was aware of the continuing debate concerning the grounded theory method, this study was predominantly guided by the original method developed by Glaser and Strauss (1967) but also described techniques used in subsequent works of both Glaser (1978, 1992, 1998), Strauss (1987) and Strauss and Corbin (1990, 1998). Strauss (1987) and Morse and Richards (2002) supported the application of the grounded theory method in this way because it allowed the researcher to discover differences between Glaser and Strauss' approaches and to avoid the belief that there was only one way to use this method. According to Morse and Richards (2002), to use only one method prevented the researcher from discovering new ways of working with the grounded theory method.

Glaser and Strauss (1967) highlighted the usefulness of the grounded theory method when the research aimed to explain and predict participants' behaviour. They made it clear that the aim of the grounded theory method was to develop a substantive or formal theory. However, theory development was viewed to be beyond the scope of this master's thesis. The grounded theory method was, therefore, chosen for this research because it facilitated the identification of a core category and the relationship of the core category to the identified subcategories. The utilisation of the grounded theory method allowed the discovery of possibly new phenomena and helped explain what it was like to live with a mental illness in rural Western Australia.

## **2.5: Data collection**

Data were collected using semi-structured interviews with young adults on their experience of living with a mental illness in rural Western Australia. In addition, demographic data were obtained about the participants from the interviews. How participants were selected, their characteristics, how they were recruited, how the interviews were conducted and other data collection methods, such as field notes and literature, will now be described.

### **2.5.1: Selection and characteristics of participants**

Participants were selected according to their experience of living with a mental illness using purposeful and theoretical sampling techniques. Participants

were young adults between 18 and 30 years old, with a mean age of 26 years, who had been diagnosed with a mental disorder. They lived in the Midwest of Western Australia at the time of the interview. This study concentrated on participants from an Anglo-Saxon background who spoke English as a first language so that no formal interpreters were needed. Nine young adults met the selection criteria. Theoretical sampling was used to guide the selection of participants and to direct data collection, i.e. what type of questions to ask. Theoretical sampling is the “sampling on the basis of concepts that have proven theoretical relevance to the evolving [theoretical findings]” (Strauss & Corbin, 1990, p. 176).

Other characteristics of participants were also noted. Four participants were female and five were male. Three participants lived alone, four participants lived with one or both parents, one lived with his spouse and the last participant lived with her sibling. Three participants were parents but only two participants had their children living with them. Only two participants worked at the time of the interview as unskilled workers. Although the remaining seven participants were not working, most had previously worked in a range of jobs including in professional positions.

The onset of the mental disorder was different for each participant and ranged from early childhood to late adolescence. One participant pinpointed a date two years prior to the interview at the age of 26. The major mental disorders experienced by participants were depression, bipolar disorder, schizophrenia and agoraphobia. In addition, participants also had diagnoses of attention deficit hyperactivity disorder, substance-induced psychotic disorder, substance dependence and elements of personality disorder. The diagnostic criteria according to the DSM-IV-TR are presented in Appendix A. Seven participants reported having attempted suicide.

Participants described the number and type of mental health services used. Most of these services were in locations outside the study area. Mental health services used at the time of the interview were: a psychiatrist, community mental health nurses, a general practitioner and a psychologist. However, five participants were not using any mental health services at the time of the interview.

Initially participants were sought out to take part in the study by letter (see Appendix C) and an information sheet (see Appendix D) outlining the proposed study, which were sent to the Nurse Manager of the Community Mental Health Services in the Midwest of Western Australia and to the Manager of Baptist Care, a

non-governmental support group. In addition, advertisements were placed in local newspapers explaining the study and inviting people to participate. Furthermore, the following organisations and professionals serving people with mental disorders were contacted: Grow (support group for people with a mental disorder), Midwest Yellow Ribbon for Life (promoting suicide awareness), Midwest Men's Health (a Health Department funded support group for men), Drug and Alcohol Team (supporting people with alcohol and drug problems), general practitioners, psychologists, pharmacists, Greenough Regional Prison, Camella Guest House (a hostel providing cheap accommodation), Mission Employment (an employment agency) and Centrelink (a government agency delivering a range of services including social security payments). The advertisements produced the only response and all participants for this study were recruited from this source. When some of the above organisations and health professionals were contacted to elicit the reason for no one coming forward to take part in the study from these sources they said that they had had no clients who met the selection criteria.

### **2.5.2: Research interviews**

Participants were interviewed between January and August 2003. The interviews ranged in length from 50 minutes to one hour and 50 minutes with a mean of one hour and 10 minutes. All interviews were conducted in a private, mutually agreed on location with adequate lighting and hearing distance. Six participants were interviewed at their home at a pre-arranged time that was convenient to them. Two participants were interviewed in a private office at the Combined University Centre of Rural Health, and one participant was interviewed in a private office at the local college for their convenience.

All participants were interviewed separately. The format of all interviews was semi-structured and open-ended (see Appendix G). The questions focused on what it was like to live with a mental illness. All interviews commenced with the following question: "Tell me about yourself". After the participant had said what they wanted to say additional questions were asked seeking clarification and further detail. The researcher employed active listening skills such as an open posture and affirming what the participants said by nodding and approving remarks. The researcher later reviewed the interviews to see whether all questions were open-

ended and whether any leading questions had unduly influenced the response of the participants.

### 2.5.3: Field notes

In addition to interviews, data were generated through the use of field notes (Streubert & Carpenter, 1999). The researcher noted down what she had seen or thought about, complementing the data obtained in the interviews. The field notes contained information on the environmental setting, the demeanour of and the type of communication used by participants, and the researcher's assessment of the willingness and ability of participants to consent to the interview. The following is an example of a field note documented during data collection:

#### Field note P1, 16.1.03

P1 had seen the advertisement in the newspaper and asked Mission Employment to ring me up and let me know that she was interested in participating in the study. I rang her home number (she couldn't ring out herself) and made an appointment for the next day at 3 pm at her house. She asked for the interview to be at her house because she didn't have transport. I arrived and before I opened the gate to the garden, she put her dog away to the back of the house. She introduced herself and invited me in to have a cup of tea. The interview took place on the veranda. The house was an old weatherboard house, looking cosy inside. The adjacent garden was enclosed by a tall brick wall (she called this the "great wall of China" later) and although traffic noise was audible, the area was sheltered and private. No one interrupted us during the one and three quarter hours I was there. She had three animals, the dog mentioned above, a black cat that was very friendly and came to be stroked, and a white rabbit in a cage on the table at which we sat. I noted down the animals because I thought they would give a purpose to her life. But this was not the case as was revealed in the interview.

I introduced myself and said that I was a nurse working at TAFE teaching nursing. I explained the purpose of the study and produced the consent form. I explained about the importance of her point of view and that it would help health professionals. She started talking straightaway, without being prompted, about her suicide attempts, her family and her de facto's successful suicide. In addition, there had been two suicides in her family. Things poured out as if she had been waiting to tell someone. She showed me a poem she had written (reproduced below) and gave consent for it to be used in the study. Most of what she said before the tape was switched on was repeated later. I explained the consent form and gave her the information sheet, which she read and then she signed the consent form. She remarked that the study was a good idea.

Her history: She attempted suicide for the first time at the age of 14 by slashing her wrists. She was diagnosed at 21 with depression and agoraphobia and is now 28. I believe she also had manic episodes according



to some of her remarks. She met her de facto at the age of 16 and he committed suicide by hanging when she was 23. She found him (later described on the tape). He was Aboriginal, which may explain why she was not allowed to attend his funeral due to death threats by his relatives.

Once the tape was switched on she hesitated slightly and started talking. From then on she talked freely without much prompting. I nodded my head repeatedly and waited for her to talk rather than ask many questions. The taped interview took one and a-quarter hours. Eye contact was fleeting and brief. She smoked only two cigarettes during the nearly two hours I was with her out of politeness for me, a non-smoker.

She did cry twice during the interview but I had the impression that talking helped her. Towards the end of the interview all the tears had dried up and she appeared pleased about having talked to me. She seemed relieved that it had all come out and that someone had listened. She was interested in knowing about the findings and I said that I would inform her once I had finished the study. I said that she was very insightful, and she replied that she knew this and therefore was so frustrated at her lack of achieving her potential. She commented after the taped interview that she would like to have had female friends because male friends were just interested in 'fixing' things rather than listening. She remarked that she wanted someone who was just listening, rather than thinking of fixing things. She thanked me for listening and for my interest and said that I had been easy to talk to. She stated that she liked nurses. She escorted me to the gate, and I hugged her goodbye. I will drop by again tomorrow to give her the addresses and phone numbers of GROW and Baptist Care and return her poem.

After the interview I was relieved and happy that it had gone so well. She had been very forthcoming and articulate. I think I can get a lot of concepts from talking to her.

Her poem:

Why should I wake up  
And get out of bed,  
I close my eyes and pull  
The covers over my head.  
Why should I get up  
And shower and dress,  
Why should I cook dinner  
And clean up the mess.  
Why should I talk nicely  
And stand tall,  
Why should I get back up  
When I know I will fall.  
Why should I do anything at all  
My life has no meaning  
No purpose at all.  
Why should I smile and pretend I'm o.k  
When inside I'm dying and going  
Insane.

Signed (P 1) 3.1.03

#### **2.5.4: Literature as data**

The literature review was completed in three stages. Chenitz (1990) outlined that in qualitative research the initial review should focus on the background and significance of the study and cover the contribution of the study to existing knowledge. The initial literature review in this study was carried out for the writing of the proposal and identified a gap in research on the experience of young adults living with a mental illness in rural areas. The second literature review established the background and context of the study and reviewed readings on the grounded theory method. Literature on the substantive area, however, was not reviewed at this stage to avoid influencing the analysis. Glaser (1998) emphasised that the researcher needed to be “as free and as open as possible to discovery and to emergence of concepts, problems and interpretations from the data” (p. 67) so that the use of any preconceived ideas gleaned from the literature that did not fit or was irrelevant to the data was avoided.

The third literature review was carried out once the analysis was nearly complete and concentrated on the substantive area of the study. This part of the literature review was “woven into the [findings] as more data” (Glaser, 1998, p. 67). Both technical and non-technical literature was used as both played an important role (Strauss & Corbin, 1990). Technical literature consisted of reports of other research studies and theoretical writings, and non-technical literature comprised autobiographical writings, newspaper articles and video-recordings. This literature was used to verify the findings and to set them into the context of existing work on the subject (Chenitz, 1990).

#### **2.6: Data analysis: Data coding procedures**

A hallmark of the grounded theory method was the simultaneous coding and analysis of the data referred to as the constant comparative analysis (Glaser, 1998). Glaser (1998) described coding as assigning categories to incidents in the data. He explained that incidents were identified in a phrase or a sentence in the interviews. Joint coding and analysis lifted the data from an empirical or descriptive level to a conceptual or theoretical level (Glaser, 1978). The path from the empirical to conceptual level was not linear but creative in nature, and Glaser (1978, 1998) warned of using pathways that were too prescriptive. The coding was carried out on

three levels: Open coding, theoretical coding and selective coding. The coding methods will now be described.

### **2.6.1: Open coding**

Glaser (1978) described open coding in detail. Open coding was defined as “running the data open” or coding “different incidents into as many categories as possible” (p. 56). It was important to code all data, line by line, so that the findings gave full coverage and meaning to the data. Coding produced conceptual ideas that were the building blocks of the findings. Open coding was also as referred to as substantive coding, which consisted of categories and their properties that dealt with the substantive area (Glaser, 1998) or the actual behaviours of participants (Glaser & Strauss, 1967). Glaser (1998) referred to the grounded theory method on this level as being inductive because the findings were “rooted in data [and] not [in] an existing body of knowledge” (p. 38).

In order to analyse the data and identify concepts and their properties Glaser (1978) suggested asking the following three questions: “What is the data a study of? What category does this incident indicate? What is actually happening in the data?” (p. 57). He stated that data collection and open coding were completed when no new properties of categories or the same properties were identified in further interviews. Approximately 125 open codes were generated in this study.

### **2.6.2: Theoretical coding**

Glaser (1978) described theoretical coding as dealing with conceptual codes, which were derived from the open codes and formed the link between the data and the theoretical findings. While in open coding the data were taken apart and coded, in theoretical coding “the fractured story is weaved back together again” (Glaser, 1978, p. 72) by relating and integrating the substantive codes into theoretical codes. Theoretical codes formed the basis for the theoretical findings and it was important that they were emerging from the data and not from extraneous sources (Glaser, 1998).

The researcher examined how and why concepts and categories occurred and were related, and the properties of categories, i.e. what type and in what circumstances they occurred. In addition, phases of the process were identified. The emerging core category was then verified through theoretical sampling by asking

participants to verify the findings. Theoretical sampling is the “conscious, grounded deductive aspect of the inductive coding, collecting and analysing” (Glaser, 1998, p. 157).

Data analysis indicated that the core category was identified as “being shut out”, and represented the basic social psychological problem experienced by the majority of participants in this study. Glaser (1978) explained that the stage of theoretical coding was complete when all the data was accounted for, and all the categories subsumed into the core category. Further coding and analysis in this study revealed the basic social psychological process that participants used to manage the basic social psychological problem and three conditions that influenced the basic social psychological problem and the process.

### **2.6.3: Selective coding and theoretical saturation**

In selective coding, as described by Glaser (1978), the researcher “selectively code[s] for a core variable and cease[s] open coding” (p. 61). Once the core category was identified as the basic social psychological problem of “being shut out” the researcher delimited her coding and data collection to gather properties related to the core variable only. Glaser (1978) supported this when writing that “the core variable becomes the guide to further data collection and theoretical sampling” (p. 61), and Glaser and Strauss (1967) maintained that this analysis was a deductive process.

The core category “integrated the theoretical findings” (Glaser & Strauss, 1967, p. 93) and was described as the “main concern” (Glaser, 1978, p. 94) of participants. Glaser (1978) stated that it had the most explanatory power, was “central and related to as many categories and their properties as possible ... reoccurred frequently ... [had] clear and grabbing implications” (p. 95) and was able to be carried through to higher conceptual levels. The core category was then integrated with current scientific literature and formed the basis for the theoretical findings of this study.

Data collection was complete when saturation was reached. Saturation meant that “no additional data were found whereby ... [the researcher] could develop properties of the category” (Glaser & Strauss, 1967, p. 61). Glaser and Strauss (1967) explained that saturation did not depend on the number of participants or how often a property occurred but on how many diverse properties were identified

from the data. They pointed out that the diversity of properties was determined by the “empirical limits of the data [and] the integration and density” (p. 62) of the theoretical findings. They also mentioned that saturation did not depend on random sampling of participants or other quantitative sampling procedures because the magnitude of the properties was not a factor in determining categories or the core category. Saturation in this study was reached at the ninth interview when the description of major categories was complex and complete. As it was the mandate of this study to explore the core category and link it to sub-categories, interviewing was stopped when saturation was reached.

#### **2.6.4: The constant comparative method of analysis**

The use of the constant comparative method of analysis is a major feature of the grounded theory method. Glaser (1978) explained that when conducting the constant comparative method of analysis incidents and concepts were compared with each other. This was carried out throughout the process of data analysis and the building up of the theoretical findings. The purpose for using the constant comparative method, according to Glaser and Strauss (1967), was to ensure the findings were accurate or grounded in the data. This was achieved by generating the categories and their properties from the data, and then using the data to illustrate the findings. Another purpose was to compare the concepts and categories with their occurrence in other settings and to generalise the findings by comparing them with existing literature. The final purpose of the constant comparative method was to allow the findings to be verified as representing reality, by comparing the theoretical findings with the data at each step of the analysis.

Glaser and Strauss (1967) described four stages of using the constant comparative method. The first stage took place during open coding where each incident was compared with other incidents. Glaser and Strauss (1967) explained that this comparison of incidents was a “defining rule for the constant comparative method” (p. 106) because it lead the researcher to recognise “the full range of types or continua of the category, its dimensions, the conditions under which it is pronounced or minimized, its major consequences, its relation to other categories, and its other properties” (p.106).

Glaser and Strauss (1967) stated that in the second stage of the constant comparative method in theoretical coding, “the constant comparative units change

from comparison of incident with incident to comparison of incident with properties of the category” (p. 108). This led to categories and their properties becoming integrated or “related in many different ways, resulting in a unified whole” (p. 109). The researcher was then able to identify gaps in the findings and collect data to complete the integration (Glaser & Strauss, 1967). The third stage of the constant comparative method, used in selective coding, delimited the findings. Glaser and Strauss (1967) defined delimiting as reducing the number of categories and their properties into a smaller set of higher level concepts. This resulted in “parsimony of variables” (p. 111) and allowed the researcher to only code data relevant to the theoretical findings. The fourth stage of the constant comparative method dealt with finalising the theoretical findings and writing up the thesis.

#### **2.6.5: Theoretical memos**

Memos are an essential part of data analysis in the grounded theory method. They are the “theorising write-up of ideas about codes and their relationships as they strike the analyst while coding” (Glaser, 1978, p. 83). According to Glaser (1978), memo writing encouraged the analyst to develop conceptual ideas about the data and to identify properties of categories as well as categories themselves. Glaser (1978) stated that memos “serve to connect the data and the final analysis explicitly by conceptually raising the analytic formulation of the codes” (p. 84) and did not entail describing data or processes but “raising that description to a theoretical level” (p. 84). Through memo writing, the researcher defined the categories, discovered the criteria and conditions under which they appeared, and uncovered connections and the significance to the data and the core category (Glaser, 1978).

Another goal of memo writing, according to Glaser (1978), was to allow the researcher the freedom to develop ideas as they arose because the contents of the memos did not have to be in logical order. Memos were written in no set format, which allowed for a high degree of flexibility. Ideas were recorded at any time in any place (Glaser, 1978). Finally, memos were placed into a memo fund and sorted so that the theoretical findings crystallised and the core category emerged. The analysis, through the use of memos, could then be justified because it was grounded in the data (Glaser, 1978).

Glaser (1978) also advised that memos should be written on separate notes from the data. The researcher in this study used A4 size paper rather than index

cards to write memos and then cut them up for sorting. The A4 size did not restrict the length of the writing to a few sentences. Memo writing started after the first interview and continued until the completion of the study.

### **2.7: Researcher bias**

Qualitative research, including the grounded theory method, is liable to be influenced by the bias and subjectivity of the researcher. Bias is “any influence that produces a distortion in the results of a study” (Polit & Hungler, 1989, p. 391). However, Glaser (1992) maintained that the grounded theory method had safeguards in place to reduce bias, such as the constant comparative method, saturation and the relating of subcategories to the core category. These safeguards ensured that the findings were grounded in the data and able to explain the participants’ main concern. Glaser (1992) stressed the importance of linking the data collection, data analysis and data presentation closely together at every step of the research process so that they adjust each other to the emerging findings.

Ahern (1999) gave other tips to avoid bias. She noted that it was important for researchers to become aware of their positive or negative feelings towards the participants that might compromise neutrality. Feelings leading to bias could be anxiety, annoyance, enjoyment, guilt, disengagement or aloofness. Ahern (1999) emphasised the importance of determining the origins of these feelings so they could be separated from the research process. Chenitz and Swanson (1992) pointed out that researchers could become aware of their own feelings by noting them down in field notes and memos. Ahern (1999) noted that this process had to be ongoing throughout each phase of the research. She gave an example of how bias could occur post-analysis if the researcher paid more attention to responses from articulate participants or to participants the researcher agreed with rather than to inarticulate or disagreeable responses.

The researcher in this study, being a mental health nurse, had several assumptions, which she had to avoid imposing on participants. To be aware of her assumptions, the researcher wrote down her preconceived ideas and assumptions before the study commenced. For example, she thought that consumers living in the community were looked after well by the health care system, and that treatment in the community was effective. She thought that hallucinations and delusions were important in the consumers’ lives and would be prominently talked about, and that

consumers did not like taking medications due to the side effects. During the analysis the researcher realised that the participants did not share her assumption that most mental disorders were life long conditions as they expected to become well in the near future. This realisation changed the focus of her analysis.

### **2.8: Theoretical sensitivity**

The development of theoretical sensitivity is important in qualitative research. Strauss and Corbin (1998) defined theoretical sensitivity as “the ability [of the researcher] to respond to the subtle nuances of, and cues to, meanings of data” (p. 35). Theoretical sensitivity depended on the researcher’s knowledge and experience with the phenomena under study (Glaser, 1978). Glaser (1978) pointed out the advantage of theoretical sensitivity in that the researcher was able to “uncover data that otherwise might be overlooked” (p. 39). Glaser (1978) stated that theoretical sensitivity “forms guidelines and reference points which the researcher uses to deductively formulate questions which may then elicit data that leads to inductive concepts being formulated later” (p. 39). Theoretical sensitivity, therefore, was not only used during data collection but also during coding of the data. However, researchers should be careful that they stayed detached enough from the data to be able to analyse and recognise theoretical concepts (Glaser & Strauss, 1967).

In this study, the researcher’s theoretical sensitivity consisted of having been educated and working as a mental health nurse with mature age mental health consumers who were hospitalised, and as a lecturer in nursing including mental health nursing. The researcher had in-depth knowledge of the medical model of mental health, which was based on the two classification systems, DSM-IV-TR and the IDC-10. She was also aware of theoretical models regarding suicidal behaviour and models exploring the link between mental disorders and alcohol and illicit drug taking. However, her knowledge and experience was limited with regards to care of young adults with a mental illness living in the community, and she had not previously conducted interviews with people with a mental disorder exploring their experience in any setting. This mix of expertise but lack of experience in the area under study gave the researcher a balance of familiarity as well as sufficient distance to the topic to be able to see and analyse the participants’ experience from a new perspective. In addition, regular discussions with the researcher’s supervisors, who



were experienced mental health nurses, provided mentorship and guidance during coding and development of the theoretical findings.

### 2.9: Data preparation and computer management procedures

All interviews were audio-taped and transcribed verbatim. The researcher employed a typist to transcribe the interviews and then checked these transcriptions for accuracy by listening to the interviews and making any corrections to the transcript. The transcribed interviews were then imported into QRS NUD.IST (Qualitative Solutions and Research: Non-numerical Unstructured Data Indexing Searching and Theorising) Version 4. Gahan and Hannibal (1998) described QRS NUD.IST as a toolkit to help researchers manage qualitative data. The researcher used QRS NUD.IST to print out the interviews leaving a large margin on the right hand side with each line numbered. An example follows:

R: SO JUST TELL ME A BIT ABOUT	1
YOURSELF, LIKE YOU HAVE ALREADY.	2
P 3: I am * [years old], I'm a father of a little ...	3
girl, married to my wife *, been married	4
for about a year now. It hasn't been the most	5
pleasant year in my life, I've been going	6
through a lot of changes in medication and just	7
trying to stay off drugs and everything else,	8
and cigarettes and drinking, and this is going	9
to be the first time ever I've ever, I've just	10
stopped everything now but during that time	11
giving up and that's been a lot of bother.	12

The printed out interviews were then used for coding every incident into categories. All the data referring to each of the categories were then mounted onto large butcher's paper and the memos added.

### 2.10: Writing up the findings

When saturation of the data was obtained and the basic social psychological problem and the basic social psychological process were identified, the writing up of the findings began. Concepts and categories, which had emerged from the data during theoretical and selective coding and analysed in memos, were now documented to describe the basic social psychological problem and process and the conditions influencing them. The findings were illustrated by direct quotations from the interviews. The original wording of the interviews was maintained so that the participants' voice could be heard despite some unorthodox language being used.

This ensured that researcher bias did not alter the data. The following points should be noted when reading the thesis:

- Each participant in this study received a code number, for example P1.
- The same code number and the date of the interview were noted when documenting field notes pertaining to the participant, for example field note 3, 4.2.03.
- Italics denoted major conceptual terms.
- Square brackets [ ] used in direct quotations indicated information which was added by the researcher.
- Asterisks \* denoted omissions of identifying features of participants and other people, including the names of hospitals, to protect their identity.

### 2.11: Definition of terms

The terms used in this study are defined as follows:

Consumer	Olsen and Epstein (2001) stated that in the Australian context, a consumer is a person who has or is using mental health services, or has been refused mental health services when help has been sought. They pointed out that the term consumer is preferred to the term patient or client because it also has political overtones. It infers political awareness, and it is hoped that positive changes in mental health services can be brought about through input from consumers at all levels of mental health service delivery (Olsen & Epstein, 2001). Stroman (2003) defined a consumer as someone who can choose services and has the power to reject them and to complain.
Health professional	Any professional giving health care to people with a mental illness. Health professionals referred to in this study were nurses, doctors, psychologists, pharmacists and unspecified councilors.
Mental health services	Services the consumer had used or sought out from psychiatrists, mental health nurses, general practitioners, psychologists or hospitals.

Participants	The people who agreed to take part and who had experience of the phenomenon under study.
Mental disorder	The American Psychiatric Association (2000) defined mental disorder in the DSM-IV-TR as a “clinically significant behavioral or psychological syndrome or pattern that ... is associated with ... distress ... or disability” (introduction, p. xxxi) and as not being related to a general medical condition.
Mental illness	The consumer’s response to symptoms of their mental disorder (Hood & Leddy, 2003).

### **2.12: Trustworthiness, credibility and transferability**

Trustworthiness, credibility and transferability of the findings were important criteria in judging the results of this study. Results of a study are trustworthy when they “accurately represent the experiences of the study participants” (Streubert & Carpenter, p. 333). They are credible when they are believable, and transferable when they can be applied to other settings or groups of people (Polit et al., 2001). Glaser and Strauss (1967) outlined properties that indicated the results of a study were trustworthy, credible and transferable. Results must “fit the data” (Glaser, 1978, p. 4), meaning that the findings must emerge from the data and not follow preconceived ideas or theories predating the analysis. Results must be understandable to anyone who was concerned with the area under study and should be able to be applied not only to the particular circumstances of the participants but also to other situations. The fourth property allowed users to take control over their situation because it had become apparent what was going on and what to do about the identified problem.

The trustworthiness, credibility and transferability of the data in this study were ensured by selecting participants aged 18 to 30 who had the experience of living with a mental illness in rural Western Australia. Trustworthiness, credibility and transferability were also ensured by adhering closely to all stages of data collection, analysis and write up outlined in the grounded theory method such as the constant comparative method of analysis to ascertain that the categories were grounded in the data. To validate the coding the researcher’s supervisors were asked to check the coding of three interviews. As the researcher and the supervisors were

in agreement, the trustworthiness, credibility and transferability of the data were further ensured. As theoretical sampling took place, any changes to questions asked during the interviews were documented. The findings regarding the categories were verified by some of the participants. In addition, the findings were discussed with other people who had experience with the phenomenon under study.

Before commencing the study the researcher documented her preconceived ideas, assumptions and bias that might have impacted on the research process thus facilitating trustworthiness of data. In addition, the researcher established an audit trail explaining how categories were arrived at and how they related to the core category and other concepts. The researcher also ensured trustworthiness, credibility and transferability of data by developing theoretical sensitivity to recognise shades of meaning in the interviews. Lastly, trustworthiness, credibility and transferability were demonstrated by setting the findings of this study within the context of current scientific literature.

### **2.13: Ethical considerations**

The research conformed to the guidelines in the Statement on Ethical Conduct in Research Involving Humans released by the National Health and Medical Research Council (1992). These guidelines stated that with regards to participants with a mental impairment, "consent must be obtained whenever the person is sufficiently competent and where the impairment was temporary or recurrent, at a time when the impairment did not prevent the person giving or refusing consent" (p. 26). Furthermore, as the participants might have perceived themselves to be in a dependent position or unequal relationship with the researcher, the "researcher gave an assurance that refusal to participate in or a decision to withdraw from the research would not result in any discrimination, reduction in the level of care or any other penalty" (p.30).

Permission to conduct this study was obtained from the Human Research Ethics Committee of Curtin University of Technology (see Appendix E). All participants initially contacted the researcher by telephone. During this initial contact the researcher explained the purpose of the study, how the interview was to be conducted and that she was not associated with any particular mental health service. Participants were assessed for eligibility to take part, whether they had a diagnosed mental illness, what health services they had or were using and that they

were between 18 and 30 years old. On meeting the participants in person, the researcher again outlined the study. The participants were given an information sheet (see Appendix D) that explained the type and purpose of the study and the voluntary nature of their participation. They were given time to ask questions before signing the consent form (see Appendix F). They were informed that their anonymity was protected, and that the researcher was the only person who could link their names with data. No identification was recorded on the audiotape or transcribed interview. Permission was also sought from the participants to present the findings in publications. All participants signed the consent form prior to commencing the interview. All participants were given a copy of the signed consent form.

No participant was exposed to harm or experienced distress during data collection for this study. Prior to commencing the study the researcher made arrangements with a counselling service to be available if a participant experienced any high levels of distress. Some participants displayed some minor discomfort at times during the interview but were able to complete their interviews without distress. In fact, the majority of the participants expressed that their interview had been beneficial in that they were able to air their concerns and get relief by talking to the researcher about their problems.

The safety of the researcher was also an important consideration. As a standard precaution employed when conducting interviews with strangers, three interviews were carried out at public facilities where there were other people present in the building but not in the interview room. The other six interviews were conducted at the participants' home. The mothers of two participants were present in the house in another room, and one participant's friend was present in an adjacent room. During the three interviews carried out with only the participants present, the researcher made sure that an easy exit was possible. In addition, the researcher's husband knew the addresses and the telephone numbers of the location but not the names of the participants. This information was destroyed after the interviews. The researcher also rang the husband by mobile telephone after the completion of the interviews. At no time did the researcher feel unsafe or threatened in the interview situation.

To maintain confidentiality no participant was identified in the transcript or reports. The data obtained in this study were recorded and stored in a locked

cupboard and in an appropriately referenced form in accordance with the Data Storage and Retention Guidelines outlined in the National Health and Medical Research Council's (1992) in their National Statement on Ethical Conduct in Research Involving Humans. The content of the audiotapes will be erased at the end of the study and data will be retained by the researcher for five years after completion of this study.

#### **2.14: Overview of the findings**

Data analysis identified the core category of *being shut out* as the basic social psychological problem experienced by young adults living with a mental illness in rural Western Australia. The two aspects of the problem were: *being excluded* and *withdrawing from society*. *Being shut out* showed that participants were not taking part in major areas of life such as social relationships, school and work.

Data analysis also revealed that participants managed their experience of *being shut out* by embarking on the basic social psychological process of *seeking normality*. *Seeking normality* was a three-phase process that helped the participants' movement towards becoming normal members of society and allowed them, therefore, to carry out everyday activities taken for granted by other, "ordinary" people.

Three conditions were found to influence both the basic social psychological problem and the basic social psychological process: *The general population's level of knowledge, understanding and exposure to mental illness, participants' contact with health professionals and the health care system, and participants' level of support*. The basic social psychological problem and the basic social psychological process and the conditions influencing them will be presented in chapters three, four and five.

#### **2.15: Summary**

This chapter described the use of the grounded theory method of qualitative research first outlined by Glaser and Strauss (1967). In this study, the data were obtained from interviews with participants who had direct experience with living with a mental illness in rural Western Australia, from field notes and memos. The constant comparative method of analysis along with the coding procedures lead to

the emergence of the basic social psychological problem of *being shut out*, the basic social psychological process of *seeking normality* and three conditions influencing both the problem and the process. The basic social psychological problem of *being shut out* identified during data analysis will now be presented in chapter three of this thesis.

## **PART TWO**

**CHAPTER 3: THE BASIC SOCIAL PSYCHOLOGICAL PROBLEM:  
*BEING SHUT OUT***

**CHAPTER 4: THE BASIC SOCIAL PSYCHOLOGICAL PROCESS OF  
*SEEKING NORMALITY***

**CHAPTER 5: CONDITIONS INFLUENCING THE BASIC SOCIAL  
PSYCHOLOGICAL PROBLEM OF *BEING SHUT OUT* AND  
THE BASIC SOCIAL PSYCHOLOGICAL PROCESS OF  
*SEEKING NORMALITY***



## CHAPTER 3

### THE BASIC SOCIAL PSYCHOLOGICAL PROBLEM: *BEING SHUT OUT*

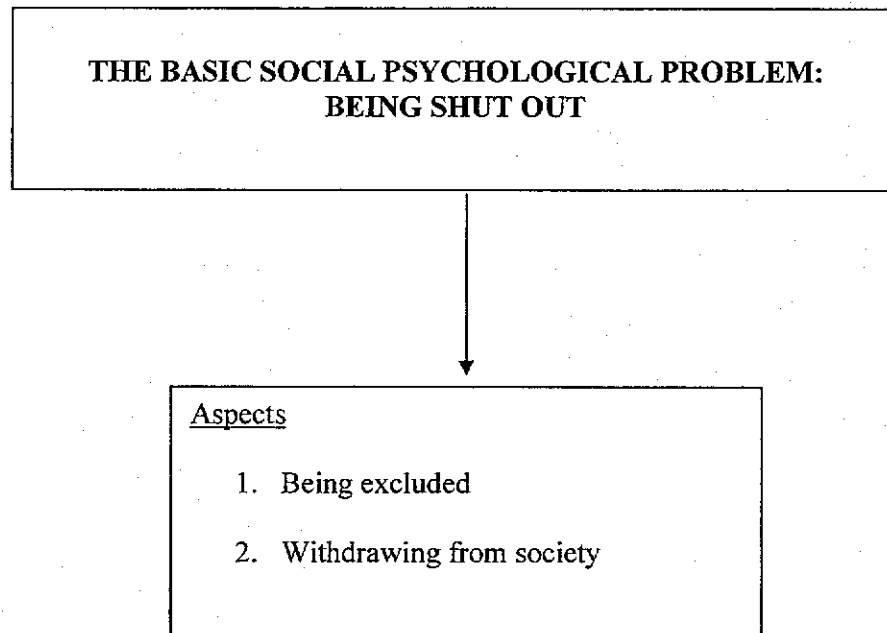
#### 3.1: An Overview

This chapter presents the basic social psychological problem experienced by young adults living with a mental illness in rural Western Australia. The basic social psychological problem was also identified as the core category. Glaser (1978) stated that the core category was the main “theme” or “concern” (p. 94) for participants. The basic social psychological problem emerging from the data was called “being shut out”. Most participants spoke of *being shut out* explicitly as a problem: “It’s very easy for somebody with a mental illness to feel shut out from society. It’s very easy for society to shut them out” (P8), and “I shut the world out” (P3). Those participants who did not directly articulate the experience of *being shut out* provided many examples that typified the similarities of the experience for them: “You’re not wanted here. You don’t have a place” (P1), “I felt alone” (P 6); as being “very lonely” (P 4, P5, P6); “I do feel isolated” (P9); “You become closed, a recluse .... I feel like a hidden outcast” (P8); “I kind of went into my shell” (P9); “[I] regressed into my house” (P2); and “[I felt] stranded and alone” (P6). Loneliness and isolation were also identified as major themes by participants living in the community in Davidson, Haglund, Stayner and Rakefeldt’s (2001) study on supported socialisation. Many other authors also mentioned isolation as a major concern identified by participants in their studies. For example, DeNiro (1995) explored the experience of alienation and loneliness of people with schizophrenia, and participants in Green, Hayes, Dickinson, Whittacker and Gilheany’s (2002) study stated that they had withdrawn from society and that friends had drifted away resulting in isolation and loneliness.

The Macquarie Dictionary (Delbridge et al., 1997) defined shut out as “to exclude, to keep out” (p. 1968). The Shorter Oxford English Dictionary (Brown, 1993) elaborated, further describing shut out as to “exclude (a person etc.) from a place ... from a situation” (p. 2849). In the context of this study, all of the above meanings of shut out were relevant. Two aspects of *being shut out* were identified: a) participants felt shut out because society excluded them, and b) participants chose to voluntarily withdraw from society because they were different and this scared them.

Both aspect of the basic social psychological problem of *being shut out* (see figure 1) will now be presented in detail and illustrated by direct quotations from participants.

**Figure 1.** The basic social psychological problem: *Being shut out*.



### 3.2: Introduction

The basic social psychological problem experienced by young adults living with a mental illness was called *being shut out* and the problem consisted of two aspects: a) being excluded, and b) withdrawing from society. The first aspect, *being excluded*, consisted of two components. The first component described how participants were excluded because they had a mental illness. Participants felt stigmatised and labelled, and they believed that they were treated differently to other people. In the second component participants were excluded because of their behaviours, which did not allow them to function well in society. In the second aspect, *withdrawing from society*, participants avoided interacting with other people because they felt different and alienated and this scared them. They were aware that their thought processes were different to others and reported that their emotions were not "sane" and that their behaviour was often unacceptable by society's standards. In addition, participants withdrew because they did not like themselves and were often repulsed by their own behaviour. Participants felt unimportant and had low levels of

self-esteem and self-confidence. The two aspects of the basic social psychological problem of *being shut out* will now be presented in detail.

### **3.3: Being excluded**

The first aspect of the basic social psychological problem of *being shut out* was called “being excluded”. *Being excluded* meant that participants were barred from social activities and interactions that other people took for granted. They were viewed as being different, labelled and stigmatised because they had a mental illness. They were unable to mix freely in society or participate fully in community life. Two components of *being excluded* were identified and both components of *being excluded* will now be detailed.

#### **3.3.1: Being excluded because of mental illness**

Participants were excluded by society because they had a mental illness. This exclusion left them feeling isolated and alone: “Isolation is all part of the illness. I see it everywhere. I’ve experienced that part of the illness” (P9), and “It [having a mental illness] sets you aside .... It makes it hard to exist in normal society” (P8). Participants were astonished at the isolating effects of their illness: “I always thought mental was maths ... but no, mental was not maths, mental was, it’s hell. It’s a lonely hell” (P1). Likewise, participants in Cutting and Henderson’s (2002) study on women’s perspective also expressed feeling isolated from society because they had a mental illness: “Mental illness itself is very isolating” (p. 709).

Participants in this study also felt excluded as a result of the stigma directed towards them by other people: “I know this, I’ve seen it first hand, [I have seen] the stigma that goes with mental illness” (P5). Participants experienced stigma when people found out that they had a mental illness and that they had been admitted to a mental health hospital. For participants the stigma remained with them after they were discharged from hospital. Therefore, participants became reluctant to seek help and tried to manage the illness themselves: “Even if I needed to go to \* [mental health hospital] I wouldn’t go to \* [mental health hospital] because you never can live it down” (P1). Furthermore, after witnessing the impact of stigma on other people participants knew they were unwilling to expose themselves to the same response:

I wouldn't be able to deal with the stigma of being in \* [mental health hospital], because there is a stigma. People are so cruel, "oh, that's the girl who's been to \* [mental health hospital]," they say about someone I used to know, you know. And that's all that she's known for, that she's been to \* [mental health hospital]. (P1)

One participant spoke of blatant social exclusion of her sister who had a mental illness. Her sister felt excluded when people refused to include her in their social chit-chat despite her attempts to be involved in the conversation around her:

I've seen it, when I went down to \* [country town] and seen my sister, like [for example], in a small country town, a lot of people know that she's got \* [mental disorder] and that [and so forth], and they actually treat her like shit [expletive]. Like [for example], she'll be talking to 'em [them] about something, not so important or anything, but they'll just cut her off half way through a sentence [bring the conversation to an abrupt end], and that [and so forth] .... [They] won't acknowledge her or, [they would] be having a talk in a group, she'll try and talk with them and just, sort of [to some extent] get excluded from the norm of society basically. (P5)

Learning from her sister's experience the participant would not tell other people about her mental disorder because she was also afraid of *being excluded*: "And that's basically what I was afraid [of] what was going to happen to me, that's why I just wouldn't tell anyone" (P5). Murphy (1998), a consumer-writer, reported similar experiences and told of her friend *being excluded* from taking part in a conversation while other people talked around him to each other. Similarly, participants in Camp, Finlay and Lyons's (2002) study on women with chronic mental health problems reported that they were deserted once people found out about their mental illness. Therefore they were cautious about disclosing their disorder to others. Participants in other studies were also reluctant to seek professional help because of the fear of stigmatisation (Link, Phelan, Bresnahan, Stueve & Pescosoli, 1999) and reported that the stigma of being a patient in a psychiatric hospital endured long after discharge (Link, Struening, Dohrenwend, Cullen & Shrout, 1989). *Being excluded* by society was also evident by the derogatory way in which people treated participants leaving them feeling rejected and devalued: "If you've got a mental illness it's like you might as well be dumb [stupid], because they [other people] ... treat you a bit silly [as if you are of low intelligence]" (P5). Therefore they chose not to disclose their illness to other people: "A lot of people don't know what I've been through [with my mental illness] and stuff [and so forth]. I've kept it to myself" (P5).

Participants explained that they were also excluded by society because they were labelled. Once labelled, participants felt like they had a tag attached to them and therefore they were treated with derision. Participants were called terms such as “weirdos” (P4, P8), “crazy” (P1, P8) and “full blown nut cases” (P3). A participant described the negative impact of labelling on him:

It’s hard to have long-time friends ... because the closer people get, the more they see, and the more evident it [the mental illness] becomes. That can either scare them or it can scare you. [Those] people [who] can get really close, end up saying “you’re a nut” ... “you’re loopy”, “you’re a nut”, “you’re crazy”, you know. Or “we’ve always known you were crazy, [participant’s name]”. You know, that sort of thing. (P8)

Participants protested that the attached labels were unjustified and wrong: “You’re not [like that], you are normal, you’re just seeing through a fog” (P8). However, their protests went unheard because of the persistence of these labels. In response, participants retreated to protect themselves against the onslaught of demeaning remarks that made them feel like an outsider. Camp et al. (2002) also found that the public viewed participants in their study as a “load of nutters”, “lunatics”, “severely mentally retarded, incapable of anything” and “some kind of idiot” (p. 827). As early as 1973, Rosenhan reported in his landmark study on the experience of healthy “pseudopatients” in the psychiatric system that “once a person is designated abnormal, all of his other behaviours and characteristics are coloured by that label” (p. 253) and that the label attached to mental illness “profoundly coloured” (p. 253) all perceptions other people had about that person. Therefore, participants in Boydell, Gladstone and Crawford’s (2002) study reported that they were very careful whom they told about their mental illness because of the fear of rejection.

Another facet of *being excluded*, described by participants, was that they were categorised and stereotyped when people found out they had a mental illness. Categorising and stereotyping meant that participants were no longer regarded as individuals but were viewed as people without a separate identity. In their experience, all people with a mental disorder were regarded as the same and no distinction was made between them: “[Society] puts ... people [with mental disorders] in categories” (P3). Participants found stereotyping difficult to live with as they believed that each person was an individual and should be treated as such: “Each person is different, dealing with everyone’s different” (P3). Likewise,

Edwards (2000), in her study on consumers' experiences, found that stereotyping affected the way people with a mental disorder were treated.

Participants also stated that the media portrayed negative images about people who had a mental illness and that these images affected the way in which other people stigmatised, labelled and stereotyped them: "The media ... portrays it [mental illness] and downplays it ... in the negative way .... It's [the media has] a very negative attitude about it [mental illness]" (P3). Similarly, participants in Camp et al.'s (2002) study found that the negative description of people with a mental disorder was due to the negative portrayal of mental illness in the media: "You feel like saying [to other people] 'Well what do you base your [false] facts on?' And they wouldn't know, they'd most probably say [we got the facts] in [*sic*] the media" (p. 828).

Participants expressed that when they were stigmatised and labelled, they found it difficult to obtain employment: "A lot of people like [for example] in jobs and that [people who offer work], I don't like to say that I've got what I've got [that I am fit to work but] they look at it like [as if] I'm some kind of freak" (P3). Equally, Alverson, Becker and Drake (1995) reported that participants could lose their jobs easily because of the pervasive stigma of having a mental illness. Another effect of stigma and labelling on participants in this study was that they felt isolated and dejected and regularly had suicidal thoughts:

It's very easy for somebody with a mental illness to feel shut out from society.... Because it's a hard thing to face ... but the problem with that is they [members of society] may find a lot of suicides can come from this kind of stigma. People who often commit suicide and people say "why did they do that? They were so happy". But nobody knows inside your brain, they say you had no reason [to commit suicide] but [you] get stuck in such a place but [where] nobody else sees it but you. It's a very scary thing. (P8)

In summary, stigmatisation and labelling occurred once other people became aware that participants had a mental illness. This resulted in participants being stereotyped and having generalisations made about their level of functioning. As a result participants felt alienated and ostracised from society because these generalisations occurred even by people who did not know them.

### 3.3.2: Being excluded because of participant's behaviour

The second component of *being excluded* occurred when participants were isolated from society because of their behaviour. As a result, they were unable to fulfil their designated family, work or community roles. They felt shunted aside and excluded from being part of society and from engaging in usual social activities. Participants stated that society excluded them because they behaved differently: “[I did not] have the ability to get up and do it ... no ‘up and atom’ to do ... things ... I didn’t have [the] energy, the inspiration to do it [something]” (P4). Other participants stated that they were not able to function because they were not mentally fit: “My brain wouldn’t just, it just wouldn’t work. I couldn’t do these things” (P2).

Participants spoke of *being excluded* because they had problems with concentration and consistency of behaviour: “I have trouble concentrating and keeping track of one subject” (P1), and “I couldn’t concentrate on my work.” (P5). These participants reported that as a result they could not focus on the task at hand: “Sometimes I could focus and do my work, other times I couldn’t focus: My mind would not focus” (P8). Inconsistency of behaviour was also an issue:

They used to tell me, “You are our best worker, \* [name], you’re the best worker we have here. You’re also the worst worker, you have the ability to be both. We need consistency”. I could not actually deliver that ‘cause [because] I was never consistent in my head. (P8)

Other researchers reported similar findings. For example, Link and Cullen confirmed, as early as 1983, in their study on social rejection of ex-mental patients that their participants’ behaviour had an impact on how society treated them. Furthermore, participants in Boydell, Gladstone and Volpe’s (2003) study on motivation and schizophrenia stated that they could not concentrate on conversations or what they were doing. Participants in this current study reported that their inability to function to acceptable standards also affected their school life leading to difficulties in learning:

[I was] not fit for that environment [at school] .... You get called “slacker”, or get a lot of report cards saying, “\* [name] could do very well if only he’d apply himself”. But you’re not mentally capable of applying yourself all the time. (P8)

They reported that they left school at an early age and experienced discrimination and lack of job opportunities because of the illness:

It [the lack of mental ability] sets you aside, yeah, even in [*sic*] school, especially in [*sic*] school actually. You don't get the chance that everybody else gets in [*sic*] school .... I found I ended up dropping out of school in year 10 .... So really, it really does set you back right from the start. Then you get out there in the world, and you haven't done a lot of schooling, foundations aren't there, and you're classed as a person with a mental disability. You haven't done well at school so you take lesser jobs, 'cause [therefore] your career paths are a lot more limited, and you don't do well in [*sic*] work either because, for the same reason you didn't do well in [*sic*] school, you can't focus properly like other people can. (P8)

Findings of this study support the literature that people with a mental illness had difficulties in behaving to expected standards of society because of their illness, and also experienced feelings of being excluded. Participants in DeNiro's (1995) study on consumers' perceived alienation from society mentioned their difficulties in fitting in at school scholastically. Likewise, Kessler, Foster, Saunders and Stang (1995) confirmed the adverse consequences of early-onset psychiatric disorders on educational attainment and reported that many people with mental disorders terminated their education early with subsequent adverse personal sequelae. Humberstone (2002) reported on the experiences of people with schizophrenia who also found themselves "left behind" (p. 370), unable to get employment and being pushed to the margins of society because of their mental illness.

#### **3.4: Withdrawing from society**

The second aspect of the basic social psychological problem of *being shut out* identified in the data analysis occurred because participants voluntarily withdrew from society. Withdrawing from society meant that participants did not want to talk to other people or establish or maintain friendships and instead retreated into their house. This occurred because participants viewed themselves as being different from other, "normal" people and felt scared: "I didn't know who I was, the kind of person. I'd look in the mirror and I really didn't recognise myself as a person, it scared me" (P3). One participant felt frightened when he saw himself as "a monster": "It's just been hard on me, extra hard on my wife 'cause [because] her husband just isn't right [mentally healthy], just, trying to drive to hell and back ... her husband is a monster" (P3). He was afraid that how he saw himself would destroy his relationship with his wife: "She wants to stay with me but staying with me, it feels like [for example], it's actually destroying her, [it is] not fair on us, it's not fair on her" (P3). As a result he



withdrew from everyone and everything: "Ninety percent of my time, [I] shut the world out" (P3). Another participant expressed similar feelings of being different and the apprehension of being singled out as abnormal made her withdraw rather than interact with other people: "I don't want people to think I'm weird. Not that I ... I try to be as normal as possible, but if someone gets to know you closer, it's harder [to hide that you are mentally ill]" (P4). Most participants felt the need to hide to disguise their difference from others: "I feel like a hidden outcast in a way. I don't feel like other people, I envy most people, for they don't have to put up with the crap [nonsense] I have to in my head [being mentally ill]. I envy them a lot" (P8).

One participant felt so different from other people that she felt that she had altered into almost a non-human, as though she had mutated: "Everyday something in me wants to improve and be better, but I know I have mutated into this non-social angry being" (P1). She was afraid that she could be a menace to other people and as a result she did not want to engage with them and therefore she stayed at home: "I don't like staying at home all day, every day, by myself. But then again, that's all I know now. I don't like staying here, but I won't go out there, will I. So I'm stuck" (P1). She sat in her small garden surrounded by a high brick wall, which she called "the great wall of China" (P1). This wall gave her a sense of being hidden from the outside world. Participants in other studies also had similar views believing they were "different" (Smith, 2000, p. 155) and "monstrous" (Camp et al., 2002, p. 829). Likewise, Weiss (2001), a health professional and a consumer, wrote of being "scared, very, very scared" (p. 88).

Participants, who viewed themselves as different, referred to their thought processes as "crazy ... weird ... [and] not right" (P8). They feared that they would be mocked and ridiculed if they mixed with other people. One participant explained her abnormal thoughts in the following way:

Some of the things I think are crazy. Like, when \* [boyfriend] died [committed suicide] I thought, 'cos [because] he looked like Jesus, when he was hanging, I thought I'd killed the second coming of Christ. I pretended I was an Indian [called] Sitting Bull, and used to sit out in the paddock.... I lost my mind. (P1)

Participants stated that as a result of their thoughts their mind could not work properly: "I have poisoned my mind" (P1). One participant provided an example, using an analogy, that due to her constantly thinking along negative lines her bad

thoughts built up and turned into something like dirty, disgusting waste, and therefore she did not have the strength to be like other people:

Like [for example], every thought is a drop of water. And, one drop of water doesn't mean much, but if you keep dropping it you'll eventually get a pool, then you'll get an ocean .... If I'm thinking something good that would be a clear drop of water, but if I'm thinking something bad, like I usually do, it's a muddy drop of water, like sewerage. So I'll have an ocean full of sewerage to swim in when other people have the strength of mind to make theirs into a clear pool. (P1)

Likewise, Hensley (2002), a consumer-writer, reported that her thoughts were like a "cesspool" (p. 418). Another participant in this study isolated himself because he was scared that the whole world was out to get him: "I was more and more up against the whole world, just everything seemed like it was against me. I could tell that it was only just in my own mind and I was sort of making it all go against me" (P7). The participant reacted to his thoughts by shutting himself away from other people: "I was trying to, just trying to run away from everything, my whole life, my family, anything that I knew" (P7). Similarly, another participant shut himself out because he was apprehensive and disturbed about how he saw other people:

There's a lot of other things that come with it [the mental disorder], there's a lot of psychotic effects and that sort of thing [and similar things], that are just not right ... and [you] view people in a certain way and in a nasty way and you don't know why. Afterwards you wonder why. (P8)

Participants also chose to withdraw from family and friends because they believed that their suicidal attempts were unacceptable. They were particularly afraid that their suicide attempts would affect other people in a devastating way. One participant was appalled at the suicide notes she wrote to her parents: "I wrote quite a few suicide notes [to my family] about why I've done [tried to commit suicide], why I want to do this and that [try this method or that method]. But I'd be appalled if they read them because then they would be left with this feeling [of desperation] that I have" (P1). She added that what she had done was "insane" (P1), and she was too aghast at her actions to tell others until she had recovered from her ordeal because she was afraid of being ridiculed:

I wouldn't tell [other] people what I [have] done until six months later or something [like that] .... That's what I do, I can't tell people something that's happening now [about her suicide attempt] because it's too insane, until you look back at it, you think, I can't believe I did that, and then you tell [other] people. (P1)

Participants felt their suicide attempts further isolated them from society. However, as events surrounding suicide were too taboo to mention, they preferred to conceal their thoughts and were reticent to talk about their suicide attempts: "That attitude to do yourself harm ... the nature of it is very isolating, that's all. And it still goes on" (P9). Participants shared the general public's revulsion to death and dead bodies. They made it clear that they did not want people to find their body after a successful suicide. A participant recalled that she would have been disgusted if anyone had found her body because she was afraid of being viewed with derision: "[I] thought of gassing myself in a car, and I've got all the means to do it, but, there's a problem, I wouldn't want anyone to find it [my body]. It'd be gross [repulsive]" (P4). The participant felt repugnance by what would happen to her remains after a successful suicide:

I wouldn't want people to be picking up my body parts [after my death]. I wouldn't want people [to see them], you know, I wouldn't want the aftermath of, like [for example] someone having to cart you to a morgue, you know, sort of [to some extent], I just want gone [not be there], that's it. It would be easiest .... If there is a button for me [to press] that does disintegrate [me], yeah, probably [I would probably do it]. (P4)

Participants reacted to the fear of being different from other people by devaluing themselves. They thought of themselves as lesser beings because of these thoughts and shut themselves away from society. A participant recounted how he felt worthless: "Lots of people who have a mental illness don't feel that they are part of society, they feel like they are just gutter trash. And there's a sense of [being] alone, you're all alone" (P6). Participants believed that they could not contribute to society: "Little ants [there are so many unimportant people], there's just so many people, so one person [the participant] is not [does not make] much of a difference in the whole scheme of things really [in how the world works]" (P4). Another participant also described feeling unimportant: "Oh, it's so amazing, you know. Just a little dot on the earth I am, and so much trouble" (P1).

In addition to feeling unimportant, participants spoke of having a low level of self-esteem. They did not have a favourable opinion of themselves and did not want to associate with other people: "I was too shy, and it was all part of this low self-esteem that I've had" (P2). Another participant elaborated on the reason for her low self-esteem and linked the level of her self-esteem to her inability to go out of the house and meet people:

I don't understand this. Why can't I have self-esteem just for being here on the planet? But no, I have to be this, or do that, and have everyone like me so I can have self-esteem, you know. Why can't I just walk down the street like every other bastard [person], why do I have to feel as though I have to stay inside and not go out? I feel like there's a neon sign above my head when I go out saying all these derogatory things about me, the way I stand, the way I sit. (P1)

Most participants reported having a low level of self-confidence when meeting other people. A low level of self-confidence was expressed as lack of confidence in one's judgement, ability and power: "I don't really have a life because depression affects you in so many ways, like it takes away, it destroys your self-confidence" (P1). A low level of self-confidence made it difficult for participants to initiate interactions with other people and therefore they remained isolated: "I've never had self-confidence, never. So to me, men have always had [it] over me because I don't have the confidence to go up to somebody, you know, to meet them, to, maybe in a sexual way" (P2). Participants in other studies formed similar value judgements about themselves. For example, participants in Hedelin and Strandmark's (2001) study on elderly women's meaning of depression reported feeling worthless: "I'm nothing, I've got no value, I'm no good at all" (p. 407). Low levels of self-esteem and self-confidence were also experienced by participants in McCann's (2002) study on uncovering hope with clients who have a psychotic illness. This also resulted in these participants having difficulties in finding friends.

Participants in this current study explained that when they shut themselves out they did not leave the house: "I didn't go anywhere" (P2). Some participants reluctantly made short and occasional forays to the shops to buy food. One participant described how she did not leave the house between scheduled shopping trips even if she ran out of food:

I hadn't [been able to] even get out of the house, I would sit in the house, and every fortnight [when] I'd get paid I'd go and shop for [groceries lasting for] two weeks, buy everything I'd need for two weeks. If I run out [of groceries] I wouldn't go to the shop again, that's it, I'd wait until next week and I'd sit in the house, just doing nothing. (P4)

The same participant stated emphatically that she would not have met the researcher if the interview had occurred in a public place: "Oh, I don't go out, I wouldn't [have] like[d], if you're going to say [if you had said] ... 'meet at a coffee

shop' then I would say [have said] 'no, no way ... no, no, no, I can't, I don't [want to go there]'" (P4).

Participants' desire to shut themselves away from society had a negative impact on their relationships with other people. A participant stated that she was scared of having a long-term relationship: "I do get scared that if I was to be in a relationship, what if it all goes yuk [horribly wrong], you know. I wouldn't want that" (P4). They gave the refusal to go out as a reason for being alone and not having friends: "I know why I've got no friends, 'cause [because] I don't go out and do stuff [anything], and try and meet people, so it's really my own doing but I don't care for people" (P4). They were not able to interact appropriately with other people: "You can't handle ... having new people around you, you can't handle meeting strangers" (P8), or to communicate: "Meeting anyone new in a social setting is just extremely hard and I won't talk ... I couldn't converse [with] or look [at] anybody" (P1). Participants stopped mixing with other people and did not seek to establish new friendships: "I wouldn't let people into my life" (P4). Furthermore, participants lost friends they already had. The following participant recalled that she cut off contact with people who still wanted to see her: "I got so withdrawn and that [and so forth], 'cos [because] I didn't really want to see anyone, I was offending people by not returning their phone calls" (P5). Participants found that because they withdrew they were no longer able to sustain long-term relationships: "I had a few relationships that, you know, they weren't, they didn't last, they didn't work that well ... I couldn't hold a relationship ... together" (P9). Molta (2002), a consumer-writer, described her profound withdrawal as "[I] retreated within myself" (p. 97), and Weiss (2001) also articulated the "fear of their [other people's] reaction" (p. 88) to her mental illness. Likewise, participants in Boydell, Gladstone, et al's (2002) study stated that they feared "the possibilities of future embarrassments and failures" (p. 127) and, therefore, withdrew from opportunities to relate to other people.

Participants also withdrew because their perception of people who had a mental illness mirrored the stigmatising attitude of the general public. Therefore, they were afraid that they would identify themselves with these people. The following participant revealed that he refused to join a support group run by people with a mental illness because he himself perceived stigma against the members of this group. As a result he shut himself off from people who may have provided him with support and a venue for ventilating his feelings and helping him with his illness:

[My] attitudes and so forth [I] stigmatise things [people with a mental disorder] ... I perceive the stigma .... Yeah. I put a stigma on things [people with a mental illness]. I went there [to the support group] on two [or], three occasions. I haven't been back. I actually found their information and what they're about good. But, yeah, I haven't taken part since. (P9)

Likewise, participants in Corring and Cook's (1999) study on the meaning of client-centred care reported that people with a mental illness have stigma against other people with a mental illness and against their own illness: "Stigma of the mentally ill towards each other and ... the stigma each and everyone of us have towards ourselves and our own illness" (p. 77). Furthermore, Link, Struening, et al. (1989) confirmed in their Modified Labelling Theory that "individuals [with a mental disorder] internalise society's perceptions of what it means to be labelled mentally ill" (p. 402) and felt devalued and discriminated against. They found that people with a mental disorder responded to this "devaluation-discrimination" (p. 402) by withdrawal and secrecy. In concluding, participants in this current study withdrew from society because they viewed themselves as being different in many ways from "normal" people and excluded themselves because they were scared and dismayed by this difference.

### 3.5: Summary

Participants, who were young adults living with a mental illness in rural Western Australia, shared the common basic social psychological problem of *being shut out*. The first aspect of the problem dealt with society isolating participants and was called *being excluded*. Society excluded participants by stigmatising them, labelling them negatively and stereotyping them. Society also isolated participants because of their behaviour that did not meet the expected standards of society. Society excluded participants because they could not function adequately due to not having enough drive, not being able to concentrate or focus sufficiently on tasks and not being consistent in the standard of their work.

The second aspect of the problem was identified as participants withdrawing from society because they perceived themselves to be different from other people and this scared them. Participants shared the same attitude as the general public towards people with a mental illness. They saw themselves as different and not as good as other people. They felt different in their thoughts, emotions and behaviour. As a result participants' level of self-esteem and self-confidence was low.

Participants' experience of *being shut out* affected most areas of their lives. They did not seek help for their illness at some health care facilities, they had few friends, they were discriminated against at school and work, and they were reluctant to meet people or leave their house. In their isolation they also thought about suicide. In managing the basic social psychological problem of *being shut out* participants engaged in a basic social psychological process called *seeking normality*. This process will now be presented in chapter four of this thesis.

## CHAPTER 4

### THE BASIC SOCIAL PSYCHOLOGICAL PROCESS:

#### *SEEKING NORMALITY*

##### 4.1: An Overview

When the basic social psychological problem of *being shut out* was identified the researcher then, through data analysis, sought to identify the basic social psychological process. The basic social psychological process was the “pattern of behaviour” (Glaser, 1978, p. 97) young adults living with a mental illness in rural Western Australia engaged in to manage their experience of *being shut out*. Overwhelmingly, participants wanted to be part of society, to be “normal”, like most other people. Participants openly expressed the desire to be “normal” and to lead a “normal” life: “I wanna [want to] feel normal, and be normal” (P2), “I try to be as normal as possible” (P4) and: “[I want to] cruise [aim] for a normal life” (P3). For participants being normal meant that they were managing the problem of *being shut out* and that they were regarded as worthwhile members of society. Being normal meant that they could interact with other people without being stigmatised, labelled or feeling different. Participants explained that when they were normal they were able to function to the expected standards of society and, therefore, able to avoid discrimination and alienation. When they were normal they were then able to leave their house, find friends, sustain relationships and seek and maintain employment. Therefore, the basic social psychological process that emerged from the data was called *seeking normality*. Similarly, Pickens (1999) found in her study on people with serious mental illness that her participants expressed the desire for normality as a primary concern, i.e. they wanted to feel like other people. Other researchers have also identified that their participants longed for a normal life, such as Warren and Bell (2000) whose study identified that consumers with severe chronic mental illness wanted to live a normal life despite having a mental illness.

To clarify the meaning of the terms “seeking” and “normality” and to confirm the fit of these meanings with the data, definitions of these terms were reviewed. The Macquarie Dictionary (Delbridge et al., 1997) defined seeking as “to go in search or quest of ... to try and find by searching or endeavour ... to try to obtain ... to try to attempt (to do something)” (p. 1923). Normality was defined by The Shorter Oxford English Dictionary (Brown, 1993) as “the state or condition of being normal” and



normal as “constituting or conforming to a type or standard; regular, usual, typical; ordinary, conventional - also, physically or mentally sound, healthy” (p. 1940). In the context of this study, all of the above meanings of seeking and normality were relevant. Participants defined being normal as: “ordinary” (P9); as being: “balanced the normal way [mood wise]” (P8); and as: “your brain’s okay” (P6). Other participants used concepts that included generally accepted characteristics of normality: “[Having] a career ... run [ning] a household, hold [ing] down a job” (P8); and having: “a family, three kids [children], a big house, car, cat and dog” (P4). Participants wanted to experience normal everyday things, which they perceived most people took for granted. Further data analysis revealed that participants’ view of normality was based on the perception of themselves before the onset of their mental disorder. One participant said that she: “used to be a funny, happy girl, and I am not now” (P1). Another participant spoke of previously being: “level headed and very community [minded] ... full of life” (P5). Warren and Bell (2000), in a study on housing preferences of consumers with severe mental disorders living in the community, reported that leading a normal life, expressed as wanting independence and having a family, was central to their participants’ aspirations for the future. Likewise, Pettie and Triolo (1999), in their analysis of the recovery process from mental illness, stated that individuals with a mental disorder compared themselves with how they used to be before the onset of the disorder and made every effort to return to this former self.

Participants in this current study described moving from *being shut out* and withdrawn from society to *seeking normality* and being engaged in society. Analysis of the data revealed that the basic social psychological process of *seeking normality* consisted of three phases. The first phase was called *floundering*. Participants stated that during this phase they struggled to manage the experience of *being shut out*. They floundered because the conscious and unconscious coping strategies they used were often maladaptive and ineffective.

Participants entered the second phase of the basic social psychological process of *seeking normality* when they experienced a turning point. For several participants this turning point took the form of a significant personal crisis. Following resolution of the crisis participants realised that their way of managing the problem of *being shut out* was not working. Hence participants moved to the second phase of the basic social psychological process, entitled *taking charge*. When in this

phase, participants changed their attitude towards life and used more effective ways to manage the experience of *being shut out*. They began to evaluate what had happened to them previously and to take control over their life. When this was accomplished participants entered the third and final phase of the basic social psychological process, which was called *moving forward*. When engaged in this final phase participants consolidated their movement towards normality by planning positive changes, setting new goals and taking practical steps towards behaving in a way that was socially expected. These changes enhanced participants' ability to interact socially within society. Hence they were fulfilling their aspiration of being viewed as "normal" and thereby reducing their experience of *being shut out*. Herman (1992, cited by Baxter & Diehl, 1998) also recognised that connecting to society again was a key feature of the recovery process for people living with a mental illness. At the time of being interviewed for this study, all participants had experienced the first two phases of the basic social psychological process of *seeking normality* and six participants were engaged in the third phase. Each phase will now be described in detail (see figure 2).

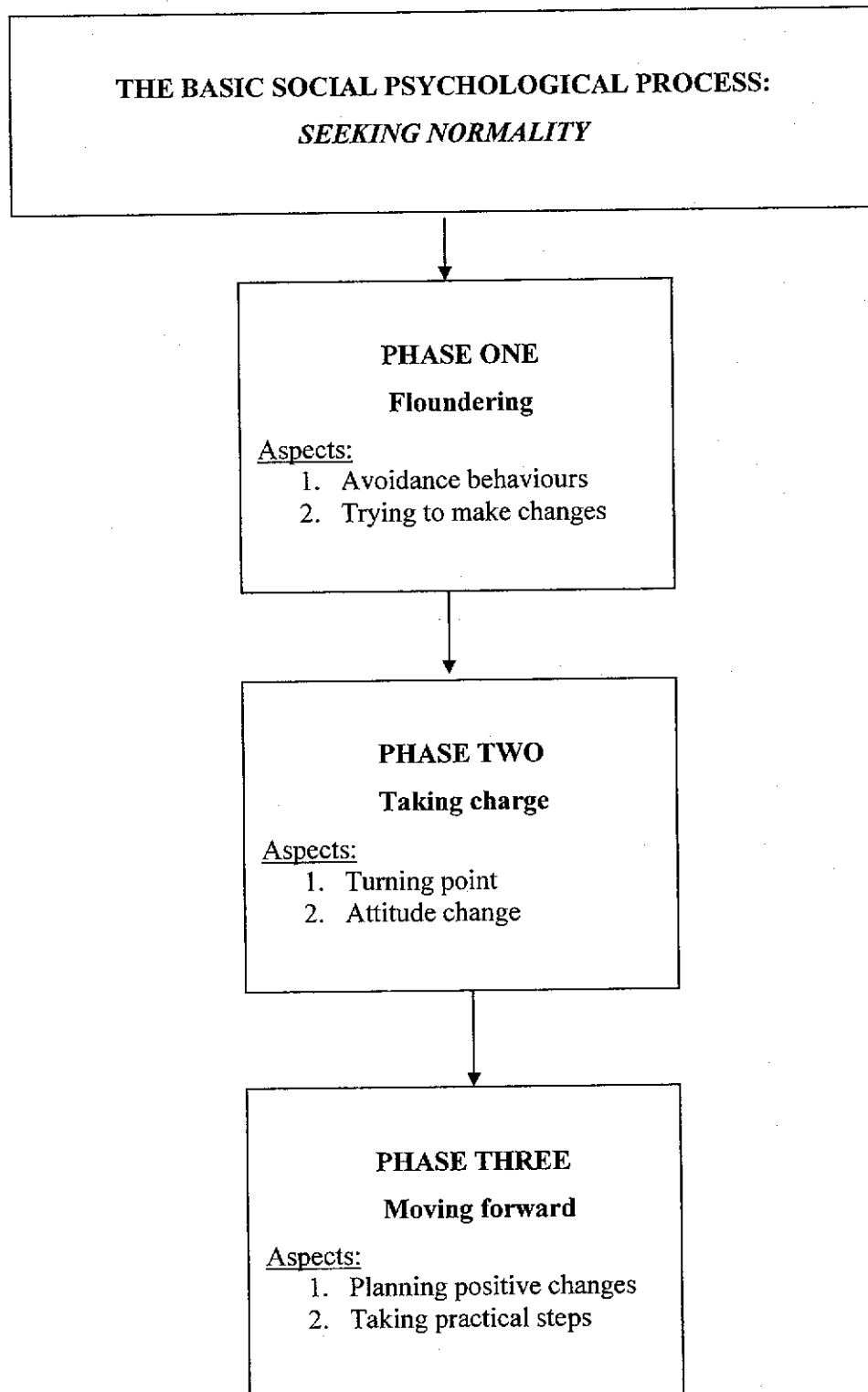
## 4.2: PHASE ONE: FLOUNDERING

### 4.2.1: Introduction

Phase one of the basic social psychological process of *seeking normality* was called *floundering*. The Shorter Oxford English Dictionary (Brown, 1993) defined floundering as to "stumble ... struggle along ... make mistakes, show confusion in thoughts and words, [to] manage something badly or with difficulty" (p. 981). In the context of this study the above meanings of *floundering* encompassed the experience of participants. Participants tried to deal with their experience of *being shut out* but were left *floundering* in their efforts to begin their integration back into society. This experience was further confirmed by Hensley (2002), a consumer-writer, who also used the term floundering to describe her experience with mental illness: "I floundered in anguish" (p. 418).

A hallmark of *floundering* was participants' perceived loss of control over their lives: "I was just out of control, just massively out of control" (P3). The loss of

**Figure 2:** The basic social psychological process: *Seeking normality*



control overwhelmed participants and left them with feelings of helplessness and hopelessness. They could not take any meaningful actions or devise any plans that were successful in reducing their experience of *being shut out*. One participant provided this insight into having no control over her own thoughts and feelings:

I can't control ... these bad thoughts and feelings. For one whole year all I thought in my head [was] one line, I just want to die, I want to die, I want to die, I want to die, I want to die, all day.... I want to die, I want to die, I want to die. I'd sit in my bed and think that. (P1)

Another participant explained that he had no control his level of energy. He referred to his energy as having no bounds and no borders: "It's [the energy is] bursting out of you ... it's like having fire coming out of your hand ... part of me was just wild and unchecked" (P8). Many participants expressed that they were unable to exert control over their own behaviour:

I stole a yacht in \* [country town] and sailed it out of the harbour, sailed it up the coast and beached it at the beach, and I just didn't even, I don't even know why I did it. I didn't even know why, I had no thought, I just walked past the harbour and [thought] "Go for a tail [do a bit of sailing]" and did it, and then I realised I shouldn't be doing this and said [to myself] "let's beach [the yacht]" and [I] beached it.... When I beached it and jumped over the bow and the wave picked up the boat and it nearly landed on top of me, a 70-foot yacht. Yeah, yeah, just done some of the craziest things without thinking, jumping off trains at full speed ... just crazy things, absolutely mad, but I just didn't think about it at the time nor about the consequences of my actions. (P3)

Participants spoke of not having control and *floundering* in other areas of their lives. They pursued dangerous, reckless activities without considering the consequences of their actions. The following participant recalled that: "Some of the things I've done, I should be dead ... and many a times I could've been killed" (P3). Most participants had used substances to excess, such as prescription medications, to help them cope with the experience of *being shut out*: "There was doctor shopping" (P6). Others used alcohol and illicit drugs: "I turned into a raging alcoholic" (P6), and: "Mull [marijuana] just absolutely, it destroyed me ... it seems to just get bigger and out of control" (P3). Likewise, participants in Koivisto, Janhonen and Vaisanen's (2003) study on consumers' experiences of psychosis reported a similar loss of control. In addition, several consumer-writers described the loss of control over their thoughts and feelings: "I cannot will control of my mind" (Moore, 2001, p.

199). Their emotions were like “blazing fires that I could not put out” (Molta, 2002, p. 98) and their thoughts about dying were obsessive (Michael, 1999).

As a result of *floundering* participants in this study were not able to function in several areas of their lives: “I’ve heard that only about 20% of people with mental illness can function, and that is scary, I don’t know whether that’s true or not, but it’s been true for me. I can’t function” (P1). For example, participants found it difficult to manage their finances: “I’ve ... just pissed it [money] all up against the wall [wasted it], basically. Wasted it ... blow [blew] it all [spent it all]” (P3), or to find employment: “You can’t work” (P1). Participants described how they floundered and two main aspects of *floundering* emerged. They were called *avoidance behaviours* and *trying to make changes*, and each of these aspects will now be discussed.

#### 4.2.2: Avoidance behaviours

The first aspect of *floundering* was the use of avoidance behaviours. *Avoidance behaviours* consisted of behavioural patterns that allowed participants to evade or deny their problems. They cocooned themselves from the outside world and avoided engaging with other people. *Avoidance behaviours* in many ways protected participants from what was happening to them and prevented them from getting hurt by other people. This behaviour allowed participants to decrease the risk of being rejected by society. Participants used both conscious and unconscious *avoidance behaviours*.

Several participants used denial, a common *avoidance behaviour*. Denial, an unconscious defence mechanism, is employed in response to a painful threat and is used to keep out conscious awareness of one’s circumstances (Sadock & Sadock, 2003). Denial is often seen as a maladaptive response but can act as a protection against unbearable reality. Participants in this study used denial in a protective manner because it was too painful for them to accept that they had a mental illness: “[I] pretended like [for example] it [mental illness] wasn’t there” (P3). However, denial was detrimental to participants as it prevented them from taking advantage of medical treatment to help them move towards normality. The following participant gave an example of how he tried to get better by seeking psychiatric help periodically. However, due to his use of denial he did not believe that he needed to access care:

It's taken three years of going back and forth between psychiatrists and me not [accepting my illness], stopping the psychiatry [stopping going to the psychiatrist], thinking I'm alright with denial [denying I am ill], that sort of thing [to some extent] .... I was in denial for many years. (P8).

Participants also employed conscious *avoidance behaviours*. These behaviours helped participants to defer tackling difficulties in dealing with other people and this gave them the false sense that everything would be alright without taking any action: "There's [*sic*] a lot of issues from past things ... that I've had for years and years [and] that I haven't even dealt with. I've just put it off ... I'll be right, she's right, she's right" (P3). Another participant decided that he would ignore difficulties brought on by his inability to relate to other people by telling himself that he did not care about these relationships: "Whereas before, I couldn't give a damn, I was just sort of [to some extent], well, who cares, you know" (P6). Instead of dealing with relationship problems the participant decided to forget about them by drinking alcohol: "And then I'd swig on my bottle of whiskey or whatever I had" (P6). Another participant avoided being confronted by other people who might disapprove of her by hiding behind her sunglasses on the way to the shops: "I go to the shops ... and I shrink. I wear my sun-glasses, because I can't see people, they can't see me" (P2).

*Avoidance behaviours* also allowed participants to shun their personal responsibility and obligations. They refused to take any responsibility for their behaviour or how they treated other people: "I was not responsible for my own life [let alone for other people's lives], I was very irresponsible, I'd [*sic*] never had any responsibility what so ever" (P3). Not taking responsibility led to participants blaming other people for their own predicament: "Yes, yes, the problem being is that I blamed everyone, I blamed everyone else, everyone I met, so that's been hard for me which doesn't help me progress or to get well" (P8).

Another *avoidance behaviour* that participants used was to pretend that problems did not exist. Participants used pretension as a way of dealing with adverse events in their lives, such as the painful memories of a boyfriend's death:

Flash back. Traumatized! Anything could remind you [of the boyfriend's death], anything. Going shopping was hard ... [I would] see the coffee that we used to buy, or just something, and you just cry in the shopping centre and you, and what can you do? Walking down the street without \* [boyfriend] is so hard. I pretend he's there. I pretend he's behind me. You lie to yourself. You pretend you're on holiday, just to cope. (P1)

Participants also used pretension as a first response to deal with minor problems occurring on a daily basis: “Catch me on a good day and I’ll seem to be quite confident [that I am able to handle life], but I’m not. It’s all pretend [*sic*]. I don’t know, does everyone pretend? I wouldn’t have a clue” (P1).

Participants also used *avoidance behaviours* to manage their emotional pain by transforming their emotional pain into physical pain. The following participant thought she could resolve her emotional pain by cutting herself so that the emotional pain could drain out: “When I ... had pain in ... my heart, in my head, I wanted it out. And it seemed it would come out by slashing [the wrists]. This is a sign that it’s coming out, now” (P1). Another participant hurt herself physically because she was able to understand and subsequently deal with physical pain much better than with the emotional pain:

When harming myself ... I knew there was [emotional] pain but ... I didn’t know how to get to it but then if the pain is physical pain it was much easier to cry over ... than to cry over a pain that you don’t understand or know, I mean, oh, it’s very terrible but, yes [this is so]. (P4)

Participants found that the emotional pain remained, and after harming themselves they had to deal with the physical injury as well as the emotional upset. As a result some participants made a decision to get rid of the emotional pain on a permanent basis by attempting to take their own life: “I just had constant pains inside, felt really, really bad, and you [I] just thought suicide would end that because I’d feel horrible, and then [after death] I’d feel nothing” (P7).

Participants found that they used *avoidance behaviours* to manage their thoughts on death and suicide. They wanted to forget their suicidal ideas but they could not get rid of their obsessive thoughts about wanting to die. One participant stated that when she felt suicidal she would stay in bed for most of the day. She would try to sleep, even taking sleeping tablets if she was unable to go to sleep:

For ... three years [when I felt suicidal] I would get up at 12 [o’clock] go back to bed at three [o’clock], get up at five [o’clock], and go to bed at 10 [o’clock]; so I’d be awake for like seven or eight hours a day, and sleeping the rest. I didn’t need to sleep. I’d have to take Mogadon [a sleeping tablet] to go to sleep, but death was so, death was not going to happen, so sleep was the next best thing. But then your dreams are filled with nightmares, so there’s really no escape. (P1)

When using *avoidance behaviours* participants remained trapped in their state of *being shut out*. They were overwhelmed by what was happening to them and wanted to give up altogether: "All I really wanted to do was die! Basically, [I] didn't want anything to do with anything" (P5). But they realised that death was not the answer: "I knew it wasn't a solution" (P7). Avoiding dealing with *being shut out*, although protective, did not relieve the participants' "misery and sadness" (P1) or improve their quality of life: "My quality of life is zilch [zero]" (P1).

Participants in other studies reported the use of similar *avoidance behaviours*. Brown (1999), a consumer-writer, found that he used sleep to get away from his mental disorder and the associated pain. Participants in Weiner's (1999) study on the experience of consumers studying at university stated that they would not accept their mental illness "because it was too painful to deal with" (p. 407). The positive aspects of *avoidance behaviours* were also highlighted in other studies. Ridgway (2001) confirmed in her analysis of four consumer narratives that denial was an important stage in the recovery process and that it was seen as "a normal reaction to an overwhelming situation" (p. 337). One participant from Pickens' (1999) study also gave an account of not managing her emotional pain and distress directly but transforming it into physical pain by hurting herself: "It makes me feel better when I cut myself .... I get depressed and nothing seems to be going right. I get a razor and then it feels better" (p. 237).

#### 4.2.3: Trying to make changes

When participants found that *avoidance behaviours* were not effective in managing the experience of *being shut out* they began to actively attempt to initiate changes in their thinking and behaviour. Most of these initial attempts were unsuccessful, and the following participant recalled that once he started to deal with his problems his state of mind actually got worse: "When I started, when I went to deal with it all, the flood gates opened and I near on, I feel, I near on had a nervous breakdown within myself, [I] just flipped out [go mad]" (P3).

Participants attempted to make changes in several areas of their lives. They felt that if their thought patterns changed they would be happier and be in a better state of mind to face problems associated with *being shut out*: "And it's all in the thought patterns, but how do you change the thought patterns? I've read books about thought patterns and brain-washed myself to think I am, I love and approve of



myself, and all this stuff [things]" (P1). But their attempt to change did not work and the bad thoughts persisted and tormented them: "[You keep telling yourself] 'I hate myself, and I'm an idiot'. And you won't let yourself think good thoughts because you feel so bad that you need to be punished" (P1).

Another area identified by participants that needed changing was the lack of purpose to their life: "My life has no meaning, no purpose at all" (P1). Participants began to search for that purpose so that their life would be meaningful: "Life has to have a purpose, no matter what it is" (P1). Participants believed that having a purpose would assist them to break down the barriers of rejection and become valuable members of society. However, participants were frequently disappointed when they tried to integrate back into society and were left with feelings that they had no role to play and were useless: "The uselessness of my existence" (P1). Participants explained that finding a purpose would give them a direction in their lives: "I do not have certain directions in my life that I actually can go" (P9). Participants wanted guidance about what to do to resolve their problems but were often left feeling perplexed: "It's like ... being put in a maze without being told that you've got to get to the exit. You don't know what to do. It's like, 'what am I doing here?'" (P4). Some participants could not see any way to improve and change their lives so they chose to end it: "Because that's [suicide is] the only way out it seems, sometimes. It seems that's the only way to get better" (P6). Participants in other studies also reported that having a purpose in life was important in order to have a meaningful existence otherwise "you're just going to sit at home and do nothing" (Young & Ensing, 1999, p. 10). However, they also had problems with finding this meaning in their lives: "The whole life was cold and empty and without meaning. There was no meaning in anything" (Hedelin & Strandmark, 2001, p. 410). Participants in Neale's (2002) study reported that they tried to commit suicide because they had nothing to live for and no future and they thought that suicide was a way to deal with their problems.

A third area that was identified by participants in this current study as needing to be changed was their ability to seek out new relationships. Participants found that they used ineffective strategies in their effort at making contact with other people. The following participant used illicit drugs to get enough courage to approach other people in order to form friendships but found that it did not work: "[I] had no sort of [to some extent] social [relationships] at all, [no] social circle since

'96, '97, absolutely no social setting. Even with the amphetamines to pump me up to motivate me and be strong, to go, you know, be in a social setting" (P9).

Once participants recognised that their endeavours to make changes were not working they tried to enlist external resources to help them. Participants looked for reading material on their mental disorder, they went to workshops and spoke with different health professionals about their illness: "I studied right into it [the mental illness] ... looked everything up, I've been to seminars ... I spoken to every doctor I could possibly speak to about it" (P3). Participants sought to understand what was wrong with them so that they could take action to overcome the problem and to live a more normal life: "I went to the GP [general practitioner], and so, when she said \* [mental disorder]. I didn't understand it ... I just didn't understand what I was going through .... I did find myself being pissed off [annoyed] ... [at] not really seeing how things are related" (P9). Participants were also desperately looking for help from other groups of people: "I really need to, you know, talk it out with someone. I'm just, I want to get it [problems] out, can't hold it [in any longer]" (P3). They contacted community support groups and attended their presentations but found them unhelpful: "I mean, it's not helped me any" (P3). Similarly, participants in Kilkku, Munnukka and Lehtinen's (2003) study on the relevance of information given to consumers pointed out that once they realised that they did not have enough resources to help themselves they accepted the need of help from others.

Participants' initial steps to engage in the basic social psychological process of *seeking normality* were difficult and they found that at times they made little progress. The continual lack of success reinforced their isolation: "There was a very long stage there where I didn't have no [any] hope, I didn't think I was gonna [going to] come out the end [get over the mental illness] or anything" (P5), and they felt suicidal: "I've just wanted to take my life" (P2). Similar feelings of hopelessness were experienced by participants in Collins and Cutcliffe's (2003) study on addressing hopelessness in people with suicidal ideation, which resulted in these participants also trying to commit suicide: "[There is] no way out [except suicide]" (p. 180).

#### 4.2.4: Summary

Phase one of the basic social psychological process of *seeking normality* was called *floundering*. It occurred during the period of time before participants

experienced a turning point in their lives. The phase consisted of two aspects: *avoidance behaviours* when participants evaded dealing with their problems, and *trying to make changes* during which participants took steps to change their situation but were not making headway towards their goal of *seeking normality*. As a result of *floundering* participants' problems mounted up and, for the majority of participants, a crisis developed. They then realised that they could not continue with their previous behaviours and responses. When participants experienced a crisis they became engaged in phase two of the basic social psychological process of *seeking normality* entitled *taking charge*. This phase will now be explored.

### **4.3: PHASE TWO: TAKING CHARGE**

#### **4.3.1: Introduction**

The second phase of the basic social psychological process of *seeking normality* was called *taking charge*. The Shorter Oxford English Dictionary (Brown, 1993) defined taking charge as: "to assume control or direction" (p. 374). In the context of this study, the above meaning of *taking charge* was relevant and was experienced by participants. During this phase participants began to change their attitude towards managing their experience of living with a mental illness as a result of a significant event described as a turning point. A turning point made participants reframe their life experience to date and inspired them to make positive changes in their lives. *Taking charge* set the foundation that enabled participants to take practical steps in moving forward in their experience of *seeking normality*. Two aspects of *taking charge* emerged from the data: a) turning point, and b) attitude change. Both aspects will now be presented.

#### **4.3.2: Turning point**

Participants entered the second phase of the basic social psychological process after they experienced a crisis that was identified as a *turning point*. The *turning point* facilitated a change in how participants wanted to live with a mental illness. The Macquarie Dictionary (Delbridge et al., 1997) defined a turning point as "a point at which decisive changes take place; a critical point; a crisis" (p. 2279). In the context of this study, these definitions were relevant and an experience described by all participants. Smith (2000) in her study on the recovery process experienced by persons with persistent and severe psychiatric disability also identified the

significance of a *turning point*. Although the majority of participants in this study experienced a *turning point* when they were confronted with a significant personal crisis, some participants described the turning point as slow accumulation of several less critical events. These two aspects of experiencing a *turning point* will now be described.

#### 4.3.2.1: Turning point brought on by a significant personal crisis

Although the *turning point* was unique to each participant, for most participants it was precipitated by a significant personal crisis. This crisis was a decisive and critically important event that had a profound impact on each participant. For some participants the crisis was life-threatening as the following participant recalled when she took an overdose of tablets when trying to commit suicide: "I got to the point where I did try to take my life, though friends stopped me, and the police came and got me and that [and so forth]. That was the turning point for me, basically" (P5). Another participant recounted a different *turning point*, which occurred more gradually over a longer period of time:

It [the mental illness] scared me, one day I just woke up and I'd had enough, I was sick of being scared in my life, walking around just always paranoid of everyone and paranoid of everything ... and I started really losing control of my life, it [the mental illness] spiralled a lot worse than it had ever spiralled out of control, yeah, so I decided just if I stayed here I'd end up dead. (P3)

The crisis experienced by another participant did not threaten her life but nevertheless had a devastating effect that altered her perception of her life and her future. She found her long-term boy friend after he had committed suicide and recounted her horror at this event:

When \* [boyfriend] died ... I found him the next day, hanging in the shed .... It was so horrible. It was every emotion I've ever felt all at once, one glance, seeing him hanging there. It was every emotion. Shock! .... And it was a surge of chemicals rushing through my body, and I just fell to the floor. I just couldn't ... I had to hold him up or cut him down, try and breathe air into his mouth which was shut. Shut. Rigour mortis had set in. (P1)

For another participant a *turning point* occurred when she found out that she was pregnant. This caused her to review her life as the father of her child was already in a relationship with another woman. This caused a lot of problems, which the participant avoided by moving away: "I came to \* [country town] because the father of my baby did not [want anything to do with the baby] ... and to get out of the

situation because he was with someone else so it was pretty [awkward] ... I knew there would just be more problems" (P4). Another participant spoke of the *turning point* occurring as a result of several smaller personal crises, which he had no control over and found overwhelming:

[I] went through a relationship break down, [my girlfriend had] two abortions, also break up of relationship with other friends I had, I went through a couple of jobs and [had] been terminated and my drug use escalated .... There was a lot of turmoil at the time. (P9)

Participants reacted to the *turning point* by taking drastic action. Their initial response was to remove themselves from the situation: "I suppose it's running away from problems" (P4). Participants decided to leave everyone and everything they knew, their home town, their family and their job, in order to have any prospect of getting out of the situation: "I had to move, I had to quit my job, I had to leave my animals. I couldn't do anything but stay in hospital" (P1). Thereby they created time and space and were able to collect enough energy to take stock so that they could succeed in resolving their situation: "I decided to try and get on top of myself" (P9). Removing themselves from the crisis enabled them to concentrate solely on turning themselves around in order to begin making changes: "I wanted to make myself better and ground myself and be able to comprehensively say that I felt [that I had done something], I wanted to ... make changes ... that was my focus, a major change" (P9). Similarly, a participant in Smith's (2000) study recounted a *turning point*, which followed a significant personal crisis when she had a "horrendous and just horrible hospitalisation ... that was the *turning point* for me" (p. 151). In line with participants in this current study she then became committed to making changes to her life.

#### **4.3.2.2: Turning point as a result of a slow accumulation of disappointments**

For several participants the *turning point* was described as a more gradual process that built up over a period of time. These participants had been trying to manage their experience of *being shut out* and they were frustrated by their lack of progress. The slow accumulation of disappointments gradually built to a critical point:

Anyway, after years of abuse, verbal not physical ... Yes, people got me down because I saw the way I was being used .... I don't know if I could see it or whether I just didn't want to see it. I think it was more of a fact I didn't want

to see it. Which of course slowly made me depressed, but ... one day I'd had enough of everything. (P2)

The reaction of participants whose *turning point* occurred as a result of a gradual build-up of smaller disappointments was far less drastic than for those participants who experienced a *turning point* as a result of a significant personal crisis. Over a period of time, these participants decided to change aspects of their lives but they did not geographically remove themselves from their past. The following participant recounted that as a result of her *turning point* she stopped taking illicit drugs: "A big part was when I had decided one day to go [off illicit drugs]" (P2). In summary, participants experienced a *turning point* as a result of a significant personal crisis or following a more gradual accumulation of events which brought on a realisation that they could not manage their life as before. This attitude change will now be discussed.

#### 4.3.3: Attitude change

The second aspect of *taking charge* was identified as *attitude change*. For participants the *turning point* highlighted that their out-of-control life could not continue and that they had to take charge. In order to gain control and move forward in *seeking normality*, participants became aware that they had to change their attitude towards managing their life with a mental illness. A person's attitude is the view they hold on a range of issues in life. A change in attitude is a prerequisite to being able to think of more effective strategies to improve life and lays the foundation for a change in behaviour. A change in participants' attitude became apparent when they recognised that they could not continue with their present lifestyle: "I mean, living your life just drinking and being so selfish and like [for example], having two beautiful children and not caring, and sort of [to some extent] trying to commit suicide twice, it's just no way to live" (P6). Participants stated that their life up to now had been wasted and without purpose, and began to view the future differently: "She [the wife] helped me realise that there's more to life than just, don't know, I can't even say I was living, I was just surviving my life, most of my life I didn't remember it" (P3). Several authors also mentioned the importance of gaining control (Humberstone, 2002; Smith, 2000; Weiner, 1999; Young & Ensing, 1999). Furthermore, McCann and Clark (2004) pointed out that gaining control was a prerequisite to recovery for people with a mental illness.

The *turning point* made participants realise change was necessary and facilitated their decision to take action: “Yeah, it’s taken this long for me to ... realise what’s happening” (P6). The realisation that decisive action was necessary lifted a burden from their shoulders. They were relieved that they had finally gathered the strength and willpower to take action and this provided hope that their life could be better. To date, some participants had likened their experience of living with mental illness to being in a dark tunnel. The realisation that life could be better was compared with seeing the light at the end of this tunnel: “A bright sort of star, a light at the end of the tunnel” (P8). Participants realised that they had come out of this tunnel: “[I have] come out [at] the other end” (P2, P5), and that they were now heading in the right direction: “Getting on the right track” (P7). They realised that they could now take action that would change their lifestyle: “You have to change your ways” (P6). The realisation made them aware that their actions could be effective and that change was possible: “It’s good to have got to that point and realise, yes, there is something wrong and something can be done about it” (P8). For most participants this journey to realisation was arduous, difficult and fraught with danger and several participants tried to commit suicide during this process: “It took me five years, and a lot, a lot of mental anguish to come out this other end. It’s nearly killed me [by suicide] a few times” (P2). Likewise, Connor (1999), a consumer-writer, stated that being on the journey to wellness and recovery was “often painful [and] tortuous” (p. 84).

Participants’ *attitude change* allowed them to view their experience of *seeking normality* in a new light and to develop confidence that they could move towards achieving their goal. They now had the necessary strength of mind to make positive changes in their life: “I really wanted it, really wanted it ... with all my heart” (P2), and: “There’s been a driving force to get well” (P9). This strength gave participants the determination to take action: “If you’ve got enough determination to do it, then you can do anything” (P7). Participants in other studies also experienced an attitude change as part of their recovery process. For example, participants in Young and Ensing’s (1999) study went through a transformation with first seeing themselves as victims, using denial and running away from difficulties, to then as someone having personal responsibility and self-efficacy enabling them to deal with problems. Diehl (1995, cited by Baxter & Diehl, 1998) identified consumers’ realisation that it was “time to get going” (p. 352) as a stage of the recovery process

from mental illness, and participants in Vellenga and Christenson's (1994) study described the beginning of their recovery process as: "I see the light at the end of the tunnel with this illness of mine" (p. 369).

Participants in this study started to accept that they had a mental illness: "I've recently, well I've accepted it [being mentally ill] ... I accepted it myself" (P8). This occurred because of the education received from health professionals: "What I've learned is that the truth is the key to mental health ... basically, just [to] educate the person when they have a \* [mental disorder], to educate them, you know, this is where it lies with you" (P9). Accepting that they had a mental illness gave participants a new level of understanding and insight: "Now I understand a lot more about what is wrong with me, and actually seeking out help and trying to fix it, trying to remedy it" (P8).

Further evidence of *attitude change* was participants' realisation they had to make changes themselves: "No-one's going to help me, I've gotta [got to] do it myself" (P6). They took steps to help themselves instead of always looking to other people to help them and began to take responsibility for their own actions. A participant gave an example of how he took responsibility for getting well:

Learning what \* [mental disorder] is, how it comes about, seeing how I've played a part in it ... and I tell myself and say, "OK, there are things to be done." I can do things without [other people's help], I haven't been dejected when the medications haven't worked, 'cause [because] I just went ... "what can I do to get better?" (P9)

Participants' outlook on life became more positive as a result of their attitude change: "I can see a good future" (P8). This provided an increased level of control and empowerment. Participants expected setbacks but were optimistic that they could handle them: "[There are] dips, but there's more ups than lows [downs] so that's the good way, and you know it's right [correct]" (P4). Another participant stated that although he still experienced some symptoms of his illness he would be able to successfully manage these in the future: "We've always got the lows in life, but as long as you, I think, the main thing you need is just determination to get back up" (P7). Young and Ensing (1999) reported similar events with participants in their study accepting that they had a mental illness and starting to take responsibility for their own life instead of leaving the recovery process up to health professionals. They mentioned that "we might have some ups and downs about trying to keep doing right but if we stay on the train or keep the right focus or whatever, we can obtain



some things we want” (p. 10). Similarly, participants in Vellenga and Christenson’s (1994) study accepted that they had a mental disorder and this made them feel more normal. Furthermore, participants in Corring’s (2002) study on perspectives of people with a mental illness living in the community also pointed out that a positive approach to life was important.

In this current study, participants’ optimistic view of the future reduced their thoughts on wanting to commit suicide: “It [the thought of committing suicide] has pretty much passed, which is a relief I must say, but it has, it’s pretty much passed” (P9). Another participant regretted that she had tried to commit suicide because she could now see a future for herself which she would have missed out on: “After that [the *turning point*] I started to see the light a bit ... I realised I had been a bit hasty in what I was doing [taking an overdose]” (P5). The following participant added that due to her now positive view of the future with her young son she wanted to try and avert thinking about suicide:

Life goes on. I hope I don’t die but I don’t know what to do, it’s still, like [for example] I don’t know ... If I keep the goal of him [the son] to be a successful young man or old man or whatever man, then I should want to be around to watch it .... And that’s how I see it, just trying to override that bit in my brain that says die, die, die. I don’t know. (P4)

In summary, participants’ attitude change towards managing their experience of *being shut out* resulted in their acceptance that they had a mental illness, taking responsibility for their actions and in getting a positive outlook for the future. Their thoughts on committing suicide also receded.

#### 4.3.4: Summary

The second phase of the basic social psychological process of *seeking normality* was entitled *taking charge*. The phase had two aspects: a *turning point* and *attitude change*. Participants began *taking charge* when they realised that they had to take control of their life in order to integrate back into society. This realisation was triggered by the experience of a *turning point*. Participants experienced this *turning point* following a significant personal crisis or after a gradual accumulation of disappointments, which came to a head. Following the *turning point* participants had an *attitude change* towards their mental illness. They became confident that they could take control of their problems and this prepared them for entry into the last

phase of the basic social psychological process of *seeking normality*. This final phase of the process will now be presented.

#### **4.4: PHASE THREE: MOVING FORWARD**

##### **4.4.1: Introduction**

The third and final phase of the basic social psychological process of *seeking normality* was called *moving forward*. The Macquarie Dictionary (Delbridge et al., 1997) defined to move as: “to advance; to make progress” (p. 1408), and forward as: “onward; of or pertaining to the future” (p. 834). In the context of this study, the meaning of these definitions was applicable to those participants who at the time of being interviewed were engaged in this phase of the basic social psychological process. When participants changed their attitude and took control of their life they began to make progress by translating their newly found determination into actions. By *moving forward* participants were able to consolidate control over their lives and tackle problems with confidence. *Moving forward* allowed them to formulate plans and take practical steps to assist with their integration into society. Young and Ensing (1999) also used the term *moving forward* in their exploration of recovery from a mental illness. Likewise, Geanellos (2002), in her study of adolescents with a mental disorder, called it “forward movement” (p. 183), which involved a transformation and positive change. Similarly, Brown (1999), a consumer-writer, stated: “Since my decision to take control of my life, things have moved forward” (p. 78). This third phase of the basic social psychological process of *seeking normality* consisted of two aspects: a) planning positive changes, and b) taking practical steps. Each of these aspects will now be presented.

##### **4.4.2: Planning positive changes**

To assist them in *moving forward* participants devised plans, which allowed them to make positive changes in their way of life. The foremost plan employed by participants was to set goals: “I’ve got goals and plans” (P5), and: “I found something to figure out” (P3). All participants in this phase of the basic social psychological process formulated a plan that achieved their aim of *seeking normality*: “Just to be like everyone else .... When I’m walking down the street not to be feeling so naked and vulnerable would be nice” (P1). Participants identified other facets of

normality, for example to be happy: "Happiness is so important. I think with happiness and confidence you could become anything you wanted to" (P1), and to enjoy what they were doing: "[I want to] do something I enjoy doing" (P5). They wanted to do things that ordinary people took for granted:

To get out that gate and go out [of the house] without too much drama and panic .... Just to be really functioning and living a life where you have friends and a job and money and self esteem because you can do [all that] for yourself and go to the shop for yourself and go the bank for yourself and do everything for yourself. And not need someone to hold your hand. (P1)

Participants wanted to be law-abiding citizens contributing to society by doing what they thought was right: "I want to do the right thing" (P2), and to be: "the right kind of person" (P4). Another participant talked about the need to be useful: "You've gotta [got to] do something with your life" (P4). Other researchers also identified the importance of setting goals as an important component of living a normal life with a mental illness (Owen, Repper, Perkins & Robinson, 1998). Ninety one percent of participants in Hodges and Segal's (2002) study had set goals and found this strategy helpful. Other researchers have also reported engaging in enjoyable activities (Young & Ensing, 1999) and being happy (Hannigan, Bartlett & Clilverd, 1997) as important.

Participants in this study also had specific plans. They wanted to do further education that would lead to a career so that they could get a well-paid job and establish a daily routine: "I want to be in [have] a career and [have] a job that is good money [that earns me a good wage] but also the routine to say they go to work [I will have a routine of going to work], you know" (P4). Some participants had plans for starting up a business to make something of themselves: "I was making out [thinking of] a business and [so that I] get a lot further in life" (P7). These definitive plans made participants feel that they had moved forward towards *seeking normality* and they were relieved and happy: "Yeah, I've found what I wanted to do for the rest of my life, and it's, oh it's remarkable, it's absolutely remarkable" (P2).

Participants also had clear ideas about what they wanted in terms of material goods. They wanted to have what other normal people aspired to: "I want ... a nice house, a driver's licence, [and] a car. I want what everyone else wants, I'm no different" (P1). Participants also spoke of initiating and establishing relationships with other people. Some wanted to get married: "I'd love to be married" (P4), and have children: "I hope to ... have a family, if that is possible" (P9). Other researchers

reported that their participants wanted similar things. Mee and Sumsion (2001) confirmed the value of work as it gave people who had a mental disorder a sense of purpose and a structure in their lives. Having nice possessions, such as owning a home and a car (Young & Ensing, 1999), and having a partner (Erdner, Nyström, Severinsson & Lützén, 2002) was also seen as being important.

Participants in this current study also wanted to learn skills that would help them to handle life with a mental illness more effectively: "I have ... start[ed] to put guidelines in place in my life, something I've never had before" (P3). These skills would enable participants to overcome the negative aspects of their illness. One such skill was how to cope in adverse situations. Participants identified that they had difficulties with handling stressful situations successfully and sought to change these previously unproductive patterns of behaviour with their newly learnt coping skills: "I now have the coping skills to get out of it, out of that rut [a dreary habit], or whatever I'm in" (P2). She gave an example of how she had used these coping skills to overcome her emotional upset after an altercation with a health professional:

After I've had a bit of a vent for five minutes I can relax because I've sorted it out in my head and there's nothing more to think about. So, instead of me going over and over and over [the same event again], like I would [have done before], I can forget about it, put it away, and if it needs to come back up again then I'll bring it up. I couldn't do [that before] ... I had no skills, nothing like that, nothing at all. (P2)

Participants changed previously destructive patterns of thinking by emphasising the importance of positive thinking. Positive thinking would overcome the negative thought patterns participants had previously been prone to: "You've got to change the way you think and that [and so forth], and so [with regards to] negative thoughts, you've just got to block them and start thinking a bit more positive" (P5). They used meditation, relaxation techniques and visualisation to change their thought processes:

Like [for example], they give you all these techniques and relaxation techniques and stuff [and so forth], and at first I thought, "Oh bull [an expletive]", and I wouldn't do it, but I've learned from that. Like [for example] meditation, and things like changing your thought process and that [and so forth] and visualisation and all that, it actually works, but it takes a while to work, and it takes quite a few months practise to get it into gear [apply it properly]. But once you get out the other end [over the mental illness], you realise it does work. (P5)

Other coping skills were put into place to assist participants to tackle overbearing emotions. Some participants found listening to music and writing helpful in coping with their emotions:

Singing is good, well, for me anyway! .... Music is very good because if you sing, it seems to get out that emotion that you can't get out any other way, or whatever. I find music is a good thing. Writing is excellent for emptying your mind and getting out the anger. Like, if I have no one to talk to I'll just write .... Writing is so healing. (P1)

Participants also mentioned humour as a way to lighten up a life previously regarded as dreary. Using humour was an indication that one was on the right track to a healthy life: "I think a sense of humour in life is success, you know, is a tick for success" (P4). Participants in other studies also found that being positive reduced the number of negative thoughts they experienced (Young & Ensing, 1999). Creative writing and listening to music were also viewed as helpful (Cutting & Henderson, 2002) along with a sense of humour (Corring, 2002).

#### 4.4.3: Taking practical steps

*Taking practical steps* was the second and last aspect in the phase of *moving forward*. Participants were now ready to translate their new attitude and plans into action so that they could manage their previously out of control behaviour. *Taking practical steps* to improve their lives reinforced that participants were *taking charge* and were *moving forward*. Participants gave examples of how they took practical steps to improve their life, for example, they began to look after themselves more effectively than before: "[I] started feeding myself properly and just genuinely caring [about myself]" (P7). Participants stopped drinking alcohol, using illicit drugs and smoking cigarettes: "This is the first time I have stopped everything now" (P3).

Participants took practical steps in dealing with their medication regimes. They decided to adhere to the prescribed medications based on what they thought was beneficial and not only on the doctor's orders. Some participants emphasised the importance of taking medication to control their symptoms: "The importance of drug therapy" (P9). The following participant described how medication helped him control his limitless energy: "I actually have a feeling of part of me being closed in, like part of me has a border around it now .... [It feels] like a crazy sort of beast that's been caged. That's kind of [after a fashion] what the medication is doing" (P8). However, some participants found they were able to handle their mental disorder

without medication as the side effects bothered them: "I just put my foot down and just, after I took the overdose and that [and so forth], I just weaned myself off all drugs [medication], and just did it for myself. And I've kept myself up since [I have stayed well], and that was months and months go" (P5). Participants recognised the benefits of not drinking alcohol, not taking illicit drugs and regulating their medications. They were now able to think clearly which helped them solve problems and make rational decisions: "I've got the use of my brain ... and [able to] use reasoning, I guess that's something I've always blocked out" (P3).

*Taking practical steps* completed participants' process of *moving forward*. Their isolation was reduced and they integrated more into society. For example, they were now willing to go out of the house: "I will go to the shops if I have to ... [but] before, I wouldn't, [I] just couldn't" (P2). Other participants found work: "[I] went out and found myself a job and started working" (P7). Participants in other studies also took similar steps to move forward. They started to take care of themselves (Young & Ensing, 1999), found work (Smith, 2000), avoided using substances and took medication (Alverson, Becker & Drake, 1995).

Participants in this study pointed out that *moving forward* was difficult and at times very slow: "It's very difficult" (P4). Other participants commented on the amount of effort it took to change: "It was very hard ... it takes a lot [of effort] to change your way of thinking" (P5). Another participant stated that the effort to keep changing was ongoing: "It's a battle for me everyday" (P3). Participants highlighted that leading a normal life was much harder for someone with a mental illness: "[For] the general population, it's quite easy for them to go out and lead a normal life, but it's an actual accomplishment for somebody with a mental illness to run a household and hold down a job" (P8).

Although participants had made progress, they still had periods of doubt and made statements like: "I don't know if I ever will be as good as somebody else" (P8). They also realised that they still had further achievements to make: "I really feel that I'm a success story. [But] I haven't fully gotten there yet" (P2). However, they were confident that they would continue to make progress in *seeking normality*: "Yeah, [I have] taken quite a few steps forward actually, getting somewhere with my life now" (P7). Participants felt proud of what they had achieved: "It's just a sense of well-being I have now, a sense of well-being, knowing that I can, I'm doing what I'm doing, and I've accomplished what I've accomplished" (P2). Participants in Young

and Ensing's (1999) study agreed that it took determination and hard work to make progress, to "will yourself to make an effort" (p. 7), and experienced a sense of wellbeing as a result. Likewise, Brown (1999) found that his effort to handle life with a mental illness was ongoing: "A constant battle, something you struggle with on a daily basis" (p. 78).

Lastly, most participants in this current study felt that as they had reached this phase of *moving forward* they were now able to provide advice to others about how to live with a mental illness. Likewise, participants in Corring's (2002) study also found it important to help others. Some participants made it clear that they were taking part in this research in order to prevent others going through the same traumas. They hoped that this study would reveal insights that would be helpful to people to develop ways of *seeking normality* more easily:

I'll do anything to help people that [*sic*] are in that position [mentally ill] to incur what I did. So I'm taking part in this [study] wholeheartedly to prevent someone going through what I went through ... because ... I wouldn't wish what I had on my worst enemy, because it's just not enjoyable. (P6)

The following participant had very useful and practical advice on how to help other people with a mental illness. He advised against dismissing what people with a mental illness do: "The main thing [is] you shouldn't ... shun what they [people with a mental illness] do, [for example if] they're cutting themselves, you don't sort of [to some extent] say 'that's bad, just don't do it'" (P7). He cautioned against making decisions for people with a mental illness, emphasising that the person with the problems had to come up with their own solutions:

You can't make any decisions for them [people with a mental illness]. That just won't ever get you anywhere. You sort of [to some extent] have to help them [people with a mental illness] to make the decisions themselves .... It's not so much the person [health professional] talking that's [*sic*] supposed to come up with the answers or anything like that, it's the person that's [*sic*] got the problems, it's just by talking about them [they] can sort of [to some extent] work them out in their own head. Just by questions and things like that [for example]. (P7)

The participant pointed out that being involved in activities was very therapeutic: "If you want them to feel better, you can't just say, 'well, hey, feel better'. You've gotta [*sic*] sort of [to some extent], you know, take them to the movies or take them out with friends or, that's what helped me" (P7). The most counterproductive action to therapy was coercing people with a mental illness to do

things, as coercion could have tragic consequences: “Anytime anything is sort of [to some extent] forced on to you, it just feels like everything’s against you and you just feel like throwing away your life, ending it” (P7).

#### 4.4.4: Summary

Participants entered the final phase of the basic social psychological process of *seeking normality* when they had overcome their confusion and hesitancy in the first phase and had developed an attitude of confidence in their ability to tackle life with a mental illness in the second phase. They took practical steps towards their goal of *seeking normality* by devising plans and changing their behaviour so that they could become valuable members of society.

#### 4.5: Summary of the basic social psychological process

This study identified that participants, who were young adults with a mental illness living in rural Western Australia, shared a common basic social psychological process of *seeking normality*. By *seeking normality* participants wanted to become normal members of society. The first phase of the three-phase process, *floundering*, occurred predominantly in the time prior to the occurrence of a turning point. During this phase, participants struggled to manage the basic social psychological problem of *being shut out* and were not able to control many aspects of their lives. They tried to avoid dealing with their isolation and when they realised that this was not productive, they made attempts at dealing with their problems but found that they were not successful.

Participants engaged in the second phase of the process, entitled *taking charge*, when they experienced a turning point. A turning point occurred following a significant personal crisis or as a result of a slow accumulation of disappointments. Experiencing a turning point made participants realise that they could not manage life as before and had to change their attitude to their ability to take control of their life. They then entered the third phase, *moving forwards*, when participants planned for positive changes and took practical steps in order to reintegrate into society.

At the time of being interviewed for this study, most participants were engaged in the final phase of the basic social psychological process of *seeking normality*. Their engagement in phase three was not determined by the length of their experience with a mental illness but by their experience of *being shut out* and *seeking*



*normality* and the conditions influencing that experience. Data analysis identified three conditions that influenced participants' basic social psychological problem and basic social psychological process and these will be described in chapter five.

## CHAPTER 5

### CONDITIONS INFLUENCING THE BASIC SOCIAL PSYCHOLOGICAL PROBLEM OF *BEING SHUT OUT* AND THE BASIC SOCIAL PSYCHOLOGICAL PROCESS OF *SEEKING NORMALITY*

#### 5.1: Introduction

This chapter presents the conditions that were identified to influence young adults' experience of living with a mental illness in rural Western Australia. The data revealed that the basic social psychological problem experienced by young adults with a mental illness was called *being shut out*, and the basic social psychological process participants engaged in to manage the problem of *being shut out* was called *seeking normality*. Three conditions were identified as influencing participants' experience of living with a mental illness: a) "the general population's level of knowledge, understanding and exposure to mental illness", b) "participants' contact with health professionals and the health system", and c) "participants' level of support". Each of the three conditions will now be described.

#### 5.2.1: The general population's level of knowledge, understanding and exposure to mental illness

The first condition identified to influence both the basic social psychological problem and process was *the general population's level of knowledge, understanding and exposure to mental illness*. People who understood mental illness and its treatment helped participants to break down their isolation and these people assisted participants' movement towards *seeking normality*. Most people gain knowledge of mental illness through formal education, reading, through media productions or through personal experience of knowing a person who has a mental disorder. Some people gain knowledge based on facts and as a result become empathetic towards people with a mental illness. However, many in the general population obtain false information especially from unsympathetic media presentations and as a result develop a negative attitude and stigmatise people who have a mental disorder. A greater understanding of mental illness is obtained when individuals come in close contact with an ill person such as with a relative, friend, workmate or client. Understanding often brings about acceptance allowing participants to live more openly in society and to play a greater role in the family and in the community.

Participants explained their experience had reinforced for them that two groups of people really knew and understood what it was like to live with a mental illness. These people lived with it on a daily basis and, therefore, had first hand experience. The first group were people who had a mental illness: "It has to happen to you to fully understand what's going on" (P5). The second group were people who were regularly exposed to or lived with people who were ill such as a relative: "Most people that [*sic*] understand are people that [*sic*] have got family members who have got a mental illness, and they understand ... things [symptoms] that are going on [occurring]" (P5). This group of people were more tolerant of participants' behaviours due to their increased understanding and connection to the individual and, therefore, they did not shut participants out when they were unwell. Likewise, other researchers have reported that providing acceptance and understanding helped with the promotion of normality in people who had a mental illness (Pickens, 1999). These authors stated that the ill person felt that they were no longer alone when they met other people who understood (Geanellos, 2002). Similarly, other researchers confirmed that having a mental illness was helpful in understanding what other ill people were going through (Lammers & Happell, 2003).

Health professionals in this study played a major role in changing the general population's understanding of mental disorders and in reducing participants' exclusion from society by providing an accurate medical diagnosis. A medical diagnosis could explain and justify participants' behaviour in a context similar to other illnesses. The acceptance of a mental disorder as a medically recognised group of disorders assisted in counterbalancing the stigma and labelling that participants experienced and was helpful to them in *seeking normality*:

It was a real breath of fresh air for me ... it was really comforting in a way for them [doctors] to say to me, "we have given you a diagnosis of \* [mental illness]" because then I knew that I, it's true, you're not just crazy, you know. You're not crazy, you simply have fluctuating mood levels inside your brain that are, that create a problem for you mentally. But if they had said "sorry, look, we don't think there's anything wrong with you," I'd walk away and I'm still like this [mentally ill] and I'd wonder "well, my God, what is wrong with me, am I crazy?" So it makes you feel sane in a way, and it helps a lot. You can look back on your life and say, "well, I wasn't just mad, I wasn't a psychopath". I'm not a bad person. Anyway, it helps. (P8)

Likewise, participants in Egan, Gridley, Hood and Brew's (2003) study also wanted their mental disorders validated as a biological illness and medical condition,

and they reported that this ended their struggle to understand the symptoms they experienced. In contrast, Ridgway (2001) found that being diagnosed with a mental disorder produced a state of deep despair and hopelessness in consumers, and similarly participants in Hayne's (2003) study felt that life as they had known it had ended when they were diagnosed with a mental disorder.

Participants in this study found that relatively few members of the general population had an accurate knowledge or understanding of their illness: "As far as the general population goes, I think most people don't understand exactly what it means" (P8). As a result, some members of the public believed that mental illness was a "made up thing": "[They think] I've just been imagining [my symptoms] and making things up" (P3). In other cases, participants were called hypochondriacs, accused of pretending to be ill and of taking advantage of society's benevolent attitude towards sick people: "You're a hypochondriac, there's nothing wrong with you" (P6). Participants were depicted as unworthy members of society who did not make good friends or employees and were labelled as lazy and malingerers: "All these people who are depressed, sitting around, lying around all day doing nothing, they're just bludgers [lazy and evading responsibility]" (P5).

Participants had to defend themselves against these accusations in order to be accepted: "[Mental illness] is ... not made up ... malfunctioning made up in your head" (P8). They explained that if mental disorders were viewed in the same context as physical disabilities they would be more accepted: "It would be nice if they [members of the public] were all more aware, understanding of the fact that it [mental illness] is a disability" (P8). Another participant explained that the difference between people with a mental illness and normal people was "just skin deep" and should not affect the essence of what it meant to be human: "To view them [people with a mental illness] as being different is like to view coloured people as being different than [*sic*] white people and different [from other, normal] people" (P3). However, participants believed that some members of the public would never understand mental illness even if education was provided because their view of and attitude towards mental illness was entrenched: "They [members of the public] have their ... sort of views of things [mental illness] and stuff [and so forth], and stick to them [their views], and that's it. It doesn't matter how many ads [advertisements] you have on TV [television] or anything, it's not going to change [their mind]" (P5).

Participants in other studies also reported that people did not understand them. For example, participants in Egan et al.'s (2003) study found that even some doctors did not believe participants were genuinely ill: "He said it would all be in my mind" (p. 31). Likewise, participants were stereotyped as lazy and unproductive citizens (Corring, 2002) and accused of not wanting to work: "People said I was lazy because I sat around a lot when I did not feel well" (Murphy, 1998, p. 186). Understanding was not forthcoming because there was no physical evidence, as participants in Walker and Seasons' (2002) study on supported housing explained: "You don't have a wheelchair" (p. 144).

In this study, the general population's difficulty in understanding mental disorders was rooted in the fact that these disorders could not always be explained scientifically. For example, the cause of many types of mental disorders was unknown: "I don't know [what caused my mental disorder], I sort of think it's genetic, my environment, my experience and my lack of support all in one" (P1). The mental disorder could start for no apparent reason: "All these mood swings ... didn't really seem to have any reason why they came there. They just seemed to pass of their own accord [volition]" (P7). Without a clearly identifiable cause the public regarded participants' complaints as groundless:

The thing about humans is that if they can see it, they'll believe it .... It is hard because ... there's no actual physical symptoms ... it's all in what you say, and whether they [other people] believe what you say or not. There's no actual physical symptoms to back it [the mental illness] up. That makes it very hard [to prove that you have a mental illness] ... but it's there and it has been there for a long time ... throughout history. (P8)

Participants reported that their complaints were often dismissed as insignificant and trifling: "The physical thing is there to be seen, and if you're just crying over something [else], then you're just a silly little girl, you know" (P1). People with a mental illness were treated differently and were second in line after patients with a physical illness to get attention and treatment: "The physically ill patients will get the oil [attention], you know what I mean; the squeakiest wheel will get the oil" (P1). Participants in other studies reported similar experiences. McNair, Hight, Hickie and Davenport (2002) found in their review of data collected from community meetings that the absence of any medical signs contributed to the public not accepting mental illnesses as "real" (p. 71). They gave an example of a person with a severe mental illness who had injured himself arriving in casualty and being

told by the health professional: "You'll have to wait; we only treat sick people here" (p. 72).

In summary, *the general population's level of knowledge, understanding and exposure to mental illness* was a condition that influenced the basic social psychological problem of *being shut out* and the basic social psychological process of *seeking normality*. When *the general population's level of knowledge, understanding and exposure to mental illness* was high, participants felt accepted and were therefore less isolated and treated more like ordinary human beings. However, when *the general population's level of knowledge, understanding and exposure to mental illness* was low participants felt that their valid complaints were dismissed. This left them distressed, and they felt unrecognised and abandoned in no man's land.

### **5.3: Participants' contact with health professionals and with the health care system**

The second condition influencing the basic social psychological problem and process was *participants' contact with health professionals and with the health care system*. Participants provided differing views on how this contact influenced their experience of living with a mental illness and this influence was related to four areas. These were: a) health professionals showed respect, b) health professionals' abuse of power, c) inadequate health care, and d) the quality of health services. Each area of this condition will now be described.

#### **5.3.1: Health professionals showed respect**

Several participants reported that health professionals treated them with respect. When someone is treated with respect it means they are shown esteem, regard, consideration, common courtesy and are treated as a valued person. Being shown respect by health professionals reduced participants' experience of *being shut out* and made participants feel like normal, ordinary human beings. Respect was shown in a variety of ways right from when participants first engaged with health professionals. The following participant recalled that when he entered his doctor's surgery he was made to feel welcome by the doctor's demeanour, which put him at ease. This made him feel like he was accepted and a valued customer:

[I] found him [the doctor] to be very receptive and he was very easy going. He's been very warming [had a very warm attitude to participant] ... [and] very welcoming, he was just very patient, you know. The patient doctor relationship was very friendly, and his attitude I found to be very calming, very easy. (P9)

Respect was also evident in other interactions with health professionals. Some health professionals treated participants in the same way they would treat any other person: "They [nurses] don't treat you like a nut [a person who has a mental disorder]. They're all very patient, nice people" (P8). The following participant felt respected because she was treated like an equal: "I [was] looking forward to talking to him [the doctor] like [for example] that just the way he talked to me about things, or I would talk to him about things" (P4). During the consultation participants sensed respect when they were listened to: "They'll [the nurses] sit there, and they'll listen to everything you have to say" (P8). Participants felt respected when health professionals took participants' opinion into account and allowed them to find their own solutions: "What was really good was they [the mental health nurses] wouldn't very often say something very great to me, they'd more ask questions and sort of [to some extent] draw it out" (P7). Participants valued the non-judgemental attitude of some health professionals: "They'd never say if anything was wrong or if anything was right" (P7).

Being respected was also a common theme in other studies on the contact between consumers and health professionals. Participants in Pennebaker, Vogels, Browton and Anderson's (2000) study on consumer satisfaction of mental health services in Western Australia also stressed that being treated with respect was important: "It is respect that I want most" (p. 35). Similarly, participants in other studies gave examples of how they were treated with respect. For example, they were treated like equals: "He [the nurse] was like one of us ... he never put himself above us" (Geanellos, 2002, p. 177), they were listened to by health professionals (McCann & Baker, 2001), or they were encouraged to explore their own ideas, which made them feel that they were taken seriously: "She [the nurse] would listen to what was important to me and what I think should happen" (O'Brien, 2001, p. 181). Participants also reported on the positive attitude of some health professionals: "[The nurses] were not judgemental, you were who you were and they accepted you as you were" (Geanellos, 2002, p. 180).

Respect by health professionals in this current study also meant that participants felt empowered rather than helpless with regards to their treatment. Some health professionals were guiding participants rather than telling them what to do when helping them to overcome aspects of their mental illness. The following participant outlined how her doctor showed her how to change her negative thinking: "He [the doctor] would like [for example] help me see ... that there are different ways of thinking, you know" (P4). Other health professionals taught participants coping skills by showing support and sharing their experience: "A lot of that [getting better] has to do with ... what I've been taught, basically, by these ladies [mental health nurses and the manager of a non-governmental organisation]. With their experience behind them, they've helped me come along to where I am" (P2). Motivating participants to move towards normality was also done by health professionals taking a coaching role and empowering participants to make progress: "It's not a matter of them [mental health nurses] pushing you by the backside, it's a matter of you taking fairy steps, and you wanting to take those steps" (P2).

Participants mentioned how they had felt respected when health professionals regarded them as special people. Health professionals showed this regard in their caring manner: "You can see they [nurses] care about it and that's why they become a nurse [*sic*], they comfort [you] and just approach you in a different manner, you [can] feel [that], just the air about them, they're different" (P3). Participants explained that the caring attitude shown by health professionals had increased their self-esteem and self-worth and made them feel like a valued client: "They [the nurses] were so caring and understanding that it actually made me feel good" (P6).

Another beneficial effect of the respectful attitude of health professionals was that participants trusted them and they started to talk about their problems: "I knew she [the nurse] was a great person, [otherwise] I don't think I would have opened up as much and talked about how I felt with things" (P4). Some participants persisted with treatment for many years due to the respectful attitude of health professionals: "[For] five years ... mental health [nurses] were there for me to go in, talk about the bad things, the good things, what was going on, and think of ways on how to get over that ... [they] did play a big part [in me getting better]" (P2).

Participants felt immensely grateful for the respect shown by health professionals: "I'm feeling quite blessed to have the support [from health professionals] I have now to help me through it [the mental illness]" (P8). Likewise,



participants in other studies reported how health professionals had encouraged them to take an active part in their treatment. Participants in Svedberg, Jormfeldt and Arvidsson's (2003) study on consumers' conceptions of how health processes were promoted in mental health nursing liked the health professionals' guidance in changing their negative thoughts into something positive: "They [nurses] make me see things differently .... Then I can have aha-reactions [understand what is going on] ... so that I can change direction" (p. 452). Similarly, adolescent participants in Geanellos (2002, citing Geanellos, 1997) reported that they valued nurses who "encouraged you ... guided you ... never drove you" (p. 178). Participants also highlighted the nurses' commitment and engagement (Svedberg et al., 2003) and stated that the health professionals' belief in the participant led to a higher level of self-esteem (Hörberg, Brunt & Axelsson, 2004). Participants in other studies also felt grateful for the attention they received from health professionals (Roper, 2003).

### **5.3.2: Health professionals' abuse of power**

While some participants reported positive experiences from their interaction with health professionals, other participants found the interaction increased their isolation and was counterproductive in managing the problem of *being shut out*. Participants stated that some health professionals regarded themselves as more powerful and then abused that power: "I felt I was inferior to him [the doctor] and he looked down on me" (P3). Power confers authority, influence and control over people. The exertion of power makes others feel helpless. People with power seem unassailable to the powerless who feel that they cannot question or challenge them. An unequal power relationship does not foster an environment that motivates ill people to get better. Likewise, Egan et al. (2003), in their analysis of consumer-nurse relationships, affirmed the centrality of power and control in interactions between consumers and health professionals, and participants in their study rarely directly questioned or confronted health professionals. The abuse of power by health professionals in this current study ranged from relatively mild disinterest to talking down to participants, ordering them to do things and overstepping the mark professionally and this aspect will now be discussed.

### 5.3.2.1: Health professionals were not interested

Participants gave many examples of how they were made to feel subservient in their relationship with health professionals. One prominent area was that health professionals were disinterested in interacting appropriately with participants and showed little concern for the problems of the patients that were coming to seek help. As a result participants felt neglected and uncared for because their needs and concerns were disregarded. The following participant complained of his doctor's disinterest in communicating with him: "[He] didn't have much rapport, couldn't remember any names, I just wasn't pleased with going to him" (P9). Another participant recalled how her concerns were ignored and disregarded when she stated that medications "had a bad effect" (P5) on her. She claimed that the health professionals did not listen to her protests about her medication: "But they [health professionals] wouldn't listen .... Their idea [is that there is] no alternative to anything [other than medication], you have to take these drugs for your own sake, and [they] don't look at anything else" (P5). As a result the participant stopped the medication without telling the doctor because she feared being denigrated: "Because they'd give you the biggest lecture and try and tell you what's good for you" (P5).

Participants recounted other instances of the disinterest displayed by health professionals. The following participant was upset that his doctor disregarded his needs. He had expected that his doctor would put him in contact with a counselling service in addition to the medication he was prescribed. However, the doctor insisted on just prescribing medication, and the participant felt that his concerns were brushed aside as he was pushed out of the door:

I had no counselling to go along with the medication, and he never put that in place [arranged counselling], he just gave me the medication and then [said that I had to] go and [he] said if you need counselling "go and get it". He never tried to put me in contact with counsellors, just "there's your prescription, how are you feeling?" [I've] told him how I'm [was] feeling, he'd sit there and write it down, write up a script [prescription] and [said] "see ya [you] later, see you in six months". (P3)

Participants also encountered health professionals who were disinterested in educating them about their illness and what they could do to get better. The following participant wanted education about her medications but did not receive any: "I asked him [doctor] for some information about \* [medication] but he forgot to give it to me" (P1). As a result participants were angry with health professionals at

not having received any education because they were convinced that education would have contributed to making a faster recovery from their illness:

I had a lot of anger to do with doctors from that [lack of education] ... there was nothing to say this is what's gone wrong ... [or] what has to be done to get well and so on. Now, anger looking back that I wasn't informed on the sort of story [on mental illness] and the evidence from the word go [from the beginning of my illness], and how it progressed from there [on the course of the illness] .... If I'd known what I'd known [what I know now], what it [mental illness] is about, where could I be now, so. (P9)

Likewise, participants in other studies gave examples of being treated with disinterest by health professionals. Participants in Egan et al.'s (2003) study stated that their problems were ignored: "The psychiatrist ... didn't talk about any of the issues that were happening. He just said that I need to stay on the Arapax [*sic*] and that 'you've just got to face these things and deal with them yourself'" (p. 31). Moreover, participants in other studies found that health professionals were almost exclusively focused on given medications, the "depersonalised 'pill' approach" (O'Toole et al., 2004, p. 324) and reported that prescribing medications was just "a cop out" (Cutting & Henderson, 2002, p. 710) because doctors did not know what else to do and because counselling was not available. Furthermore, participants in other studies also reported that they did not get sufficient education about their illness and in particular about their medications: "[I] found it hard to get any information [about the side effects of medication]" (Egan et al., 2003, p. 31).

As a result of the disinterest shown by health professionals in this current study, participants had the impression that they did not care about them. The following participant described some nurses as cold and mechanical: "You can tell the nurses that [who] just did it as a job, just like a robot" (P3). Other participants spoke about the uncaring attitude of doctors: "You get doctors, and psychiatrists, that [*sic*] sort of [to some extent], they give you the feeling that they don't really care, themselves" (P6). The uncaring attitude was incompatible with participants' needs. They were looking for support, compassion and commitment: "What I needed most was support ... and a sense of compassion that someone actually does care about you, and really, really wants to help you" (P6). Participants stated that they would not have got to the point where they tried to commit suicide if they had experienced support and compassion from health professionals: "If I'd had that [support and compassion] a lot more frequently than I did, I probably wouldn't have tried to kill

myself twice" (P6). Similarly, participants in other studies also reported encounters with uncaring health professionals. Participants in Forchuk and Reynolds's (2001) study on consumers' reflections on the relationship with nurses felt that the nurses did not care about them: "I felt she [the nurse] did not care" (p. 49), and participants in Jackson and Stevenson's (2000) study on their perception of mental health nurses also spoke of nurses acting like robots when they were closely observing patients: "[Some nurses] are like robots. When the patient moves they follow like zombies" (p. 383). Similarly, participants in other studies wanted health professionals to be committed even during difficult times (Geanellos, 2002), and confirmed that having a nurse "looking out for me" prevented them trying to commit suicide (O'Brien, 2001, p. 180).

Participants in this current study reacted to the disinterest shown by health professionals by not communicating with them: "I hardly ever talked to him" (P3), or by not telling the truth: "You may as well manipulate them and just get it over and done with and then you avoid so much crap [nonsense]" (P5).

### **5.3.2.2: Health professionals were talking down to participants**

The unequal power relationship between participants and health professionals was also demonstrated through the way in which health professionals spoke to participants. Participants felt they were talked down to. Talking down to someone means to talk condescendingly to them from a superior position. The following participant recalled that she was talked down to when the health professional regarded her as stupid rather than in need of education: "There is a difference between treating a person like they're stupid or treating them like they might not know what they've done" (P4). Another participant felt that she was being talked down to when a nurse made inappropriate and hurtful comments. These comments reflected the nurse's disregard for the participant's point of view and mocked her feelings. The participant and other patients in the hospital were talking about their problems, and the participant tried to explain the emotional pain she felt: "I feel hurt, I have to cut myself, you know, I have to hurt myself [and I was] trying to explain how it felt" (P4). By exposing her inner feelings the participant opened up to the group. She let her self-defences down trusting others to respect her feelings. In this vulnerable state she heard the nurse say: "She [the nurse] just said 'get over it', like [for example], you know, 'your dad's a different person, your mum's a different

person, just get over it' [we all have problems and have to get over them]" (P4). The participant felt outraged at the crude and insensitive response of this nurse, which the participant noticed was rooted in her superior attitude:

I just felt so angry at her, if I could have, if I was a person who would lash out, like [for example] I'm not [that kind of person], but if I was, I would have lashed out at her and just, how dare she say that though, as a nurse, just saying "get over it", 'cause [because] you can't just get over it if you can't get it [the pain] out of your head, you know .... I found her attitude was so uppity [above herself] about things. (P4)

Similarly, participants in other studies had encountered the same superior attitude displayed by health professionals (Moyle, 2003) and as a result they felt inferior: "Superiority, he [the nurse] puts himself above us" (Hörberg et al., 2004, p. 13). Participants in Roper's (2003) study spoke of how they were talked to as if they were a child or a dog.

### **5.3.2.3: Health professionals ordered participants to do things**

Other displays of power by health professionals were even more blatant. Participants felt coerced into doing what they did not want to and were pressured into obeying the health professionals' orders. The following participant was commanded to have a shower by a nurse even though she did not want to take one at the time: "[The nurse] tried and hammered [me] with 'you've gotta [got to] have a shower'" (P4). The participant felt put down and was hurt by the nurse's orders: "Get up and have a shower sounds like 'you stink'" (P4). Likewise, Lützén (1998) gave an example of the subtle coercion nurses used when they wanted a patient to have a shower: "Take the case of this male patient, who doesn't want to wash .... I go into the room ... and say 'pew', what is it that smells in here?' It works" (p. 104). These nurses justified this behaviour by thinking: "It's for the patients own good" (p. 104) and that they knew better than the patients what was in their best interests.

In the following example the attempted coercion resulted in the participant feeling threatened if she did not follow the health professional's orders. She recalled that the doctor gave her an ultimatum by refusing to write a sick certificate unless the participant took the prescribed medication: "She [the doctor] said, 'well, I'm not going to give you a certificate unless you are going to take these drugs'" (P5). The participant felt "devastated" (P5) because she needed the certificate to get the sick allowance to live on: "I was a bit vulnerable at the time, so I basically felt threatened.

Being threatened if I didn't take these tablets when they [health professionals] wouldn't listen to anything else [I said], they said, 'no, you gotta [got to] take these tablets,' which I thought was a load of shit [nonsense]" (P5). The participant reacted to this threat by lying: "You just tell 'em [them] what they wanna [want to] hear just to stop them going on and on and just get 'em [them] off your back, and then you go off and do your own things [not take the medication]" (P5). The abuse of power shown in this example deflated any esteem the participant held for the health professional. She lost respect for the doctor when she exposed the hollowness of the advice:

I ... told 'em I was still taking the tablets ... just to stop that hassle. And they kept saying, "oh, you're doing so well and everything, on the tablets", when I wasn't even on the tablets. Yeah, that's what it takes. So I don't really have much respect for the mental health professionals. (P5)

#### 5.3.2.4: Health professionals overstepped the mark professionally

The worst abuse of power occurred when health professionals behaved unprofessionally. Treating someone unprofessionally means to act contrary to professional ethics. Participants reported some instances where health professionals took the liberty to disregard their professional codes of conduct: "She [the nurse] was very unprofessional and overstepped the mark on a lot of things" (P5). Codes of conduct cover rules of behaviour and have been formulated by professional organisations to protect the rights of clients. Unprofessional conduct does not foster trust and confidence in health professionals and prevents any therapeutic interaction from occurring. The following participant gave an example of unprofessional conduct when she came across confidentiality being violated: "It was illegal for him [health professional] to talk about anybody [else] [other patients]" (P2). Participants were shocked and repulsed about this lack of confidentiality:

[A] thing that sort of [to some extent] scared me a bit, like [for example], she'd [the nurse would] talk about other patients. Like [for example], she'd use their names and that [and so forth] and say [said], "It's OK 'cos [because] you don't know them" ... and that just sort of [to some extent] freaked me out a bit [terrified me]. I'm thinking, "well, if you talk about these people [other patients] like this, what's to say you're not talking to other people about me like this". And it's just like [for example], "no". (P5)

Participants felt that due to the lack of confidentiality they could not talk to health professionals because they did not trust them: "That [lack of confidentiality] sort of [to some extent] put me off coming forward and talking to anyone ... there

was no trust there” (P5). Participants felt that it was better for them to move away from their home town because of confidentiality issues: “I figured I’d have to move away from the problem [lack of confidentiality]” (P5). Participants felt betrayed by and were angry about the unprofessional conduct of these health professionals but they were unable to confront them because of their fragile emotional state and the powerlessness they felt: “I should have just stuck up for myself, but I was a bit vulnerable at the time” (P5). Therefore participants just withdrew from interacting with these health professionals. Similarly, participants in other studies found that some health professionals did not keep personal information confidential (Corring, 2002). Likewise they broke off relationships with them because they did not feel secure in interacting with them (Hörberg et al., 2004) and because they felt vulnerable and lacked the courage to confront the health professional directly (Roper, 2003).

#### **5.3.2.5: Curbing the abuse of power**

Participants held firm views on what to do with health professionals to curb the abuse of power. Foremost, their superior demeanour needed to be addressed: “They need an attitude change in the medical profession ... they really need an overhaul” (P3). In order to facilitate this attitude change participants advised that health professionals should be made to get more education on mental disorders:

The whole medical profession, the basically the whole mental thing and GPs [general practitioners] ... should renew their ticket [permission to practice] once every five years so they can re-learn .... You know, tickets [should] only last five years so they’re forced to update themselves. (P3)

Participants mentioned that psychologists and counsellors also needed to get further education about mental health issues: “Counsellors and ... psychologists, yeah, should be trained up to deal with those kind[s] of problems [mental health issues]” (P3). Obtaining the latest knowledge on mental disorders was important because participants wanted to be educated by health professionals about their disorder and about the latest treatment options: “The medical profession needs to be educated so that they can educate people [consumers] .... I need updates all the time ‘cause [because] there’s all those new models [treatments] coming out, there’s all those new things being found out” (P3). Likewise, participants in other studies also complained about some health professionals’ lack of education on mental health

matters: "They didn't have the depth of experience .... Mentally they couldn't really help me" (Egan et al., 2003, p. 33) and recommended that in order to affect an attitude change health professionals should attend compulsory staff/consumer forums biannually in order "to keep fresh" (Roper, 2003, p. 49).

### 5.3.3: Inadequate health care

Participants complained that they did not receive an adequate level of health care because health professionals did not help them. Helping someone means to treat their condition, to prevent harm from occurring and to provide assistance. Most participants had problems finding any help: "It's been able to find somebody who can help, somebody that [*sic*] can help you with their approach, which [*sic*] I haven't found" (P9). Participants who had found some help stated that it had been insufficient: "I've come off [come against] a lot of walls and got hardly any help 'cause [because] the Australian attitude is: 'Just get over it'" (P3). Participants felt they did not get sufficient help because health professionals refused to deal with the participants' mental health problems: "They're not really into your problem" (P5). Similarly, McNair et al. (2002) found that participants in their review of community treatments did not get help in general terms: "I suffered two years of hell and when I consulted a GP I got no help" (p. 72). Specifically, an acquaintance of Murphy (1998) was refused medication by health professionals and told to just "pull himself out of it [the depression]" (p. 186).

Participants in this current study mentioned that another reason for not getting adequate health care was the refusal of health professionals to make enough time for them: "You could tell [that] he [the doctor] was so busy and preoccupied with other things" (P5). Participants found that because health professionals were rushed participants did not feel comfortable talking about their inner feelings and felt compelled to withhold their concerns:

They [mental health professionals] always seemed really flat out and busy and that [and so forth] .... They're just like, "oh, I've got the next patient coming at this time" and that [and so forth], and they're taking off [going away]. You're meant to blurt all this information out, how you're feeling, and all this, in a set amount of time ... [and then] you don't feel like talking about it. (P5)

Participants therefore shortened their visit and relayed to health professionals only that which they wanted to hear: "I tell him what he wants to hear and get out of



there" (P5). Similarly, participants in Pollock, Grime and Mechanic's (2002) study on consumers' perceptions of their entitlement to time with their doctor felt that describing their mental health problems was a difficult and lengthy process and they could not "plunge straight into describing the symptoms" (p. 688) as they would have been able to do with a physical problem. Therefore they selected only the most pressing issues to discuss with their doctor because of time constraints.

Another area participants felt they had failed to get adequate health care was during the assessment of their illness. They stated that they had not been assessed properly: "Psychiatrists and doctors alike, and anyone in the mental [health] profession, has got to understand this, they've got to ask questions a lot deeper than they're asking .... [They need to be] asking a broader variety of questions" (P6). Participants maintained that by doing a thorough assessment, people with mental health problems could be helped more effectively: "You can actually get to the main point and sort of [to some extent], yeah, help people, help people out of a lot more effectively than they have been in the past" (P6).

Participants also reported that they had not got adequate health care because their diagnosis had been wrong. Some health professionals were too hasty with their diagnosis and the diagnosis was not correct: "They're [the doctors are] too quick to diagnose you with something, and that may not be the problem at all .... It's just wrong, it shouldn't be done like that, it's not meant to be done like that" (P6). Participants stated that a correct diagnosis was important so that appropriate treatment could be given: "[You need to] be diagnosed proper[ly] and not just [be] slapped [put] on to some tablets, try these, try that, you know, just hope for the best. Because it doesn't work" (P6). In addition, when participants disagreed with the health professional's diagnosis, their opinion was ignored and they were railroaded into accepting the health professionals' judgement: "They [the health professionals] shouldn't force their idea [onto] people [with a mental illness]" (P5).

Participants were disappointed by the inappropriate treatment they received. The following participant stated that the treatment she got was ineffective:

The doctor, his grand solution to the whole idea [the mental illness] was to knock me out for a whole week and I said, "no. I'm gonna [going to] wake up in a week and I'm gonna [going to] go aaagh [cry], just the way I am now." How can you stay [asleep] for a week anyway? What kind of blooming [expletive] drug is that? (P1)

Participants stated that the treatment with medication was often unsuitable: "I have a lot of negative views about the medication issue" (P3). Participants felt that medications were given on a trial and error basis and that they were used in an experimental manner without knowing their effectiveness:

And I didn't want to be a lab-rat either, I didn't want be like [for example], "oh there's this new medication out on the market and we'd like you to try it because we think this might help you with \* [mental illness]" .... I was just given tablets, "try this tablet, try that tablet". And "have this injection, have that injection", and it did nothing. (P6)

In addition, participants complained about the intolerable side effects of medications: "The \* injections I was on had me walking around like a zombie .... I couldn't speak properly, I couldn't walk properly. I felt a feeling of total self-pity" (P6). Therefore most participants stopped taking medications: "[The medication] wasn't too good for my health, so I weaned myself off 'em [them]" (P5). Likewise, participants in other studies had strong views on medications. Participants in Roper's (2003) study were dismissive of treatment with medications, stating that problems were not resolved by medications that induced sleep: "Instead of playing God and injecting you and then you sleep. The problem is still there when you bloody [expletive] wake up" (p. 25). Other studies also mentioned the undesirable side effects of medications as a major issue, and gave these as the most common reason for discontinuation (Stawar & Allred, 1999). Weiss (2001), a health professional who became a consumer, described the side effects as the "psychotropic prescription game" and the "medication readjustment roulette" (p. 87). Other participants reported that: "I was on such brutal medication it was really impossible for me to do anything" (Boydell et al., 2003, p. 424) and agreed that being forced to accept the health professionals' judgement on medications was detrimental to their recovery from mental illness (O'Brien, 2001).

Participants in this study regretted that they had not received adequate health care because they might have been able to recover from their mental illness much earlier: "[It] is hard to think that, well, if I had [had] someone [to help me] at the start [of my illness] that I wouldn't have gone through this ordeal" (P9). But after looking for appropriate help for a long time they had given up: "I stopped trying to look for professional help, just getting sick of it" (P3).

#### 5.3.4: Quality of health services

The quality of health services influenced participants' experience of *being shut out* and their movement towards normality. Quality indicates the excellence by which health services supply health care. High quality health services helped participants recover from their episodes of mental illness and reduced their sense of isolation. For example, participants saw the hospital as a safe haven or a refuge when they felt suicidal and they sought it out:

Yeah [the stay in hospital] was good. I went there [to the hospital] at [sic] Christmas day because I'd promised \* [boyfriend] I'd kill myself by Christmas day, and I couldn't. So I was in there at Christmas 'til [until] New Year. It was good. I could have stayed there longer. (P1)

Likewise, participants in Jackson and Stevenson's (2000) study also found the hospital to be a "place of safety" (p. 384). In addition, the following participant in this study was very impressed by the support of the Mental Health Line. The Mental Health Line provides 24 hour telephone access to people with mental health problems: "I mean I've had a few episodes where I've rung up the Mental Health Line, and they've been great, they've been absolutely fantastic" (P6).

Participants, however, found some parts of the health care system unhelpful. The following participant mentioned the lack of services for people with a mental illness: "There should be more services for people like me, who keep asking repeatedly for help but just don't get any" (P1). Payments for health services were also a concern to participants. They got the impression that the level of care was related to having private health insurance: "I don't have private health insurance, and I don't get good care from my doctor" (P1). As a result of the confusion over payments participants decided not to go to the doctor anymore: "Now I just don't even go to the doctor" (P1).

Participants were also concerned about being locked up against their will when they were suicidal or needed treatment. People with a mental illness can be involuntary detained under the Mental Health Act of 1996 in Western Australia with what is called a treatment order. The following participant recalled his stay at a hospital as an involuntary patient under a treatment order. He described it as being punitive and likened it to being in solitary confinement in a prison:

[I was] put under what's it called, [a] treatment order which is basically they [nurses] have constant watch over you. They'd have to sit there, they'd have to have someone sitting there and watching me eat, watching me sleep,

watching me shower, go to the toilet and everything like that .... [I] wasn't able to see anyone [else] .... I wasn't able really to do much at all, always lying in bed, [there were] no windows in the rooms and no windows in the showers, and light was on all night. Some nights, they'd just come in to your room for a second every now and then ... just turn the light up a little bit just to check, to make sure you're still there, and OK, then [go] back out .... It was really just horrible to have that, really difficult. (P7)

The participant reacted by doing his best to get out of the hospital. He feigned his emotional state in order to be let out and get discharged:

It was mostly just hiding my mood swings, just disguising them and pretending that I wasn't in that mood .... I didn't want anyone to know that I was having them [mood swings] .... Sort of [to some extent] wanted everyone to think that I was OK so that I could get out of there [the hospital] as quickly as possible. (P7)

Likewise, participants in Cutting and Henderson's (2002) study likened their stay in hospital to being in a prison: "It was run like a prison camp, not a hospital" (p. 708). In summary, *participants' contact with health professionals and with the health care system* was a condition that had great influence on the basic social psychological problem of *being shut out* and the basic social psychological process of *seeking normality*. Participants' respectful treatment by health professionals eased their isolation and contributed to their quest for normality. However, the majority of participants were regarded as inferior by health professionals, and this limited the effectiveness of any forthcoming help.

#### **5.4: Participants' level of support**

The *participants' level of support* was the last condition identified as influencing participants' experience of *being shut out* and their wish to become more normal. Supporting others means to give them strength, to encourage them not to lose hope, to lend assistance and to back them up when problems arise. Participants experienced various levels of support from family members, friends and groups in the community.

##### **5.4.1: Level of support from family members**

Some participants received support from family members, which cut through the rejection and loneliness they experienced from other people. The support gave them hope that not everyone had given up on them. It signalled to them that there

were still people who stood by them despite the awful things that had happened. Most participants emphasised how important the support of their family was: "I can't put more emphasis on family; family is the most important thing that you can have. If you haven't got family, you've got nothing" (P6), and "I don't have a friend closer than my family" (P4). This support, especially from parents, was overwhelming and unshakeable in the face of even the worst behaviour from participants:

I brought a lot of shame on my parents; my parents have done nothing but stand by me. All my life I put shit on them [treated them badly] but they're good people, absolutely beautiful people and, I mean most mothers would have just wiped their hands off me but my mum's been through a hell of a lot with me. I brought more stress to my parents than all my brothers and sister put together .... [But] they keep on having me back. (P3)

Participants detailed how their family members provided support. Some family members were supportive by just "being there" when participants needed them: "My family were always there for me" (P6). Participants mentioned that family members looked after them when they were unable to care for themselves: "Mum has looked after me; she's just been there for everything. I didn't have the resources, nothing like that" (P2). This prevented participants being admitted to hospital: "If I didn't have my mother there, I would have to be in a mental institute. Just can't take care of myself in that state [when mentally ill]" (P8).

Participants mentioned that family members were able to give support because of their special attributes, for example their patience with participants' troublesome behaviour: "My step-dad and my mum has [sic] been ... very patient over the years" (P8). In addition, parents continued to show love and affection even in difficult times: "They [parents] have a lot of love ... for me.... They can express warmth" (P9). Participants therefore regarded family members as the main group of people who gave them hope that recovery from their mental illness was possible: "They [the parents] think I'll eventually spring back, recover" (P8). Without their family's support participants were convinced that they would have despaired and been driven to suicide: "If I did not have my family, I'd be dead. I would have completely killed myself" (P6). Participants showed their gratitude by wanting to give support back to their family members once they were well enough: "So it's her [the mother's] turn now; well, once I get fit [well enough] it's her turn [to be looked after by me]. She can come and live with me if she likes" (P2).

Similarly, participants in other studies also had support from their families and pointed out the benefits of this support. These participants reported that their parents were the only people still in contact with them (Humberstone, 2002), and this support gave them hope that they would recover: “[Family] always stood by me ... because some day I would get better. That really helped” (Brown, 1999, p. 76). Participants in Green et al.’s (2002) study on the role and impact of social relationships upon consumers’ well-being stated that they would have had to spend more time in hospital without the unconditional support from their relatives, and they made it clear what a vital role family members played by just “being there” (p. 570). Likewise, participants in other studies pointed to similar benefits of being supported. They confirmed that when relatives truly believed in them and “invested in them” (p. 424) it had an impact on their self-esteem and hope (Boydell et al., 2003), and was vital for maintaining health and quality of life (Corring, 2002). Moreover, they were grateful to their parents for their love and constant presence (Tsai, 2002).

However, some participants in this study reported that their family was not supportive: “Mum and dad, they are not there for me” (P1). This lack of support increased their experience of *being shut out* and participants felt rejected and devastated: “I’ve been really angry and upset and sad and rejected and left out” (P1). Participants speculated that the reason why their family was not supportive lay in the family members’ own attitude and failings. Some parents were ashamed: “They were ashamed of you” (P1) or felt guilty about what had happened to participants and were unable to do something constructive about it: “They might feel like [for example] guilty” (P1). The following participant thought that her parents were not able to handle the participant’s mental illness: “They can’t handle it” (P1).

Family members used several methods to show their lack of support, some avoiding having anything to do with participants. The following participant recalled that after one of her suicide attempts, the participant’s sister notified the parents but they did not want to come and be with her: “My mum went camping ... and dad said something but he did not come” (P1). Another participant had similar experiences: “[The father] just pushed us away ... and it didn’t help” (P4). Therefore participants concluded that these parents did not care about what happened to them: “I s’pose [suppose] my parents didn’t care what we were in the end” (P4).

Some families used more forceful methods to push participants away. The mother of the following participant used the underhanded tactic of audio-taping her daughter's abnormal behaviour to get her admitted to hospital:

She's [the mother has] got a little tape recorder and she taped me without me knowing. And she gets it and goes, "I'm gonna [going to] put you in \* [major mental health hospital] now". And I just crushed open the cassette tape, I just couldn't believe she would do that to me, my own mother, would tape me and try to lock me up. (P1)

Similarly, participants in Megivern, Pellerito and Mowbray's (2003) study on the experience of university students living with a mental disorder also reported a lack of support from family members resulting in isolation. Likewise, participants in Alexander's (2001) study on relationships of men with depression felt abandoned and rejected by relatives.

#### **5.4.2: Level of support from people other than family members**

Participants reported that the action of their friends also influenced their experience of *being shut out*. Some participants who did not have family support turned to friends for help. Friends provided what family would not, for example a caring attitude: "I had quite a few friends come by, friends who really cared about me, and that was in the main how I got through it [the mental illness], just having people to talk to, and people that really genuinely cared" (P7).

However, most participants were disappointed by the lack of support received by their friends. In contrast to family members who used various methods of shooing participants away, most friends simply drifted away without giving a reason: "[There has been a] break up of relationships with ... friends I had" (P9). Even intimate relationships broke up: "And in the end, we had love for each other, but it was just, we couldn't be together. She left" (P9). Some participants reported that even when friends were around to help they did not have the skills to respond appropriately to the needs of participants. A participant recalled that when friends found her during one of her suicide attempts they did not know how to console her:

I just, the first two or three years [of that particular episode], every single day I would attempt it, to die, and I'd feel so frustrated because I couldn't. People would catch me, and it would be so humiliating. They wouldn't say anything, they'd say, "do you want a cigarette?" or something stupid, and there I am with a noose around my neck, howling like a dog, with no dignity and - and nothing to live for. (P1)

#### 5.4.3: Support groups in the community

Some participants had contact with support groups. Support groups in the broadest sense are organisations set up either by governmental or non-governmental bodies to assist specific groups of people. They provide education, counselling and practical help with finding employment and housing. The support groups used by participants were serving members of the general public. They, therefore, did not carry the stigma associated with support groups assisting people with mental disorders specifically. The majority of participants found support groups very helpful. The following participant explained that the only people coming to visit her were from an employment agency: "I have two ladies [employees] from Mission Employment [an employment agency] who come in and see me once a month to see that I'm still alive and alright ... these two ladies are helping me as much as they can" (P1). Another participant related the help he received from STAY (Short Stay Accommodation for Youth) who not only found accommodation for him but also provided counselling: "I was with STAY for a while and ... they set me up in my own apartment and just sort of kept an eye on me" (P7).

Only one participant found an organisation, Centrelink, a government agency delivering a range of services including social security payments, unhelpful. She had asked for workshops to improve her mental state but none were organised: "I wrote a letter to Centrelink saying, 'please help me. I do nothing, I have nothing, I want help. Like a course on self esteem and motivation, and anger management.' And I haven't received those courses" (P1).

In conclusion, the majority of participants received good support from family members but little support from other people. This left them isolated from the wider community. Participants found most support groups they had been in contact with helpful. These groups had no explicit connection to mental health services.

#### 5.5: Summary

Three conditions were identified as influencing participants' experience of *being shut out* and their desire of overcoming this experience, called *seeking normality*. The first condition was *the general population's level of knowledge, understanding and exposure to mental illness*. The majority of participants found a lack of knowledge and understanding in society and this increased their exclusion from society. The second condition was *participants' contact with the health*



*professionals and the health care system.* Likewise, the majority of participants felt rejected and mistreated by health professionals and did not get the help they wanted from the health care system, and they therefore decided to no longer continue with their treatment. The third condition was the *level of participants' support* received from relatives and non-family members. Most participants were supported only by family members but abandoned by friends. The three conditions, on the whole, compounded participants' experience of *being shut out* and impacted adversely on their experience of *seeking normality*.

## **PART THREE**

### **CHAPTER 6: DISCUSSION, IMPLICATIONS AND CONCLUSION**

## CHAPTER 6

### DISCUSSION, IMPLICATIONS AND CONCLUSION

#### 6.1: Introduction

The final objective of this thesis was to set the finding of *seeking normality* to overcome *being shut out* within the context of relevant scientific literature. Although literature has been presented throughout the results section of this thesis, further theories and research findings relevant to the findings in this study are presented. These include Goffman's (1968) theory on stigma, Link, Struening, Dohrenwend, Cullen and Shrout's (1989) modified labelling theory approach to mental disorders, Baxter and Diehl's (1998) model of emotional stages in recovering from the trauma of mental illness, Marris' (1974) theory of loss and change, and Parsons' (1951) concept of the sick role. In addition, a discussion on the medical model of treating people with a mental disorder, the paradigms of rehabilitation and recovery and working collaboratively with consumers will be presented. This chapter will also outline implications based on the findings and detail the limitations and the need for further research into young adults' experience of living with a mental illness. Finally, the concluding statement of this thesis is presented.

#### 6.2: The finding of *seeking normality* to overcome *being shut out*

The findings of this study are based on identification of the core category and its relation to subcategories. The findings identified a basic social psychological problem common to all participants, which was conceptualised as *being shut out*, and a basic social psychological process, entitled *seeking normality*, that participants engaged in to manage the problem. Two aspects of the basic social psychological problem of *being shut out* emerged from the data. The first aspect of *being shut out* was called *being excluded*. Participants were excluded for two reasons. Firstly, they were excluded because they had a mental illness and hence they attracted stigma that was all pervasive and permanent. The stigmatisation of participants involved attaching derogatory labels to their mental illness and stereotyping them as outsiders. The media contributed to the stigma participants experienced. The second reason participants were excluded from society was due to their behaviour, which precluded them from functioning adequately in society. Therefore, participants were not successful at school and were unable to find sustained employment. Participants

reacted to *being excluded* by not disclosing their mental illness to others and by not seeking treatment in mental health care facilities. They also attempted suicide as a result of *being excluded*.

The second aspect of *being shut out* was entitled *withdrawing from society*. Participants actively excluded themselves from society because they saw themselves as being different from other people and this scared them. These differences were evident in their thoughts, behaviour and displayed emotions, which resulted in lowered levels of self worth, self-esteem and self-confidence. Participants tried to hide their differences by avoiding people, withdrawing from existing friendships and staying at home. Some participants thought about committing suicide as a way of withdrawing permanently.

In order to manage the experience of *being shut out* participants engaged in the basic social psychological process of *seeking normality*. They wanted a normal life and to enjoy the pleasures other people experienced. The basic social psychological process of *seeking normality* was a three-phase process and these phases were: *floundering*, *taking charge*, and *moving forward*. Participants' movement through the phases of the process was not related to the length of their illness but to their experience of *being shut out* and the conditions influencing that experience.

*Floundering*, the first phase of *seeking normality* was characterised by participants being in a state of turmoil with little control over many aspects of their lives. They could not control their thoughts, feelings, level of energy and behaviour and they engaged in risk taking behaviours, for example, taking medications and other substances to excess, which was detrimental to their level of functioning. Data analysis revealed that there were two aspects to *floundering*: *avoidance behaviours* and *trying to make changes*. Participants employed maladaptive coping responses to avoid dealing with their feelings associated with *being shut out*. They denied having a mental disorder, deferred or ignored difficulties, refused to take responsibility for their actions and blamed other people for their predicament. They pretended problems did not exist, or avoided dealing with emotional difficulties and their thoughts about committing suicide. Although *avoidance behaviours* relieved participants' anguish for a short time, they did not resolve their situation.

Participants entered the second aspect of *floundering*, identified as *trying to make changes*, when they realised that *avoidance behaviours* were not effective.

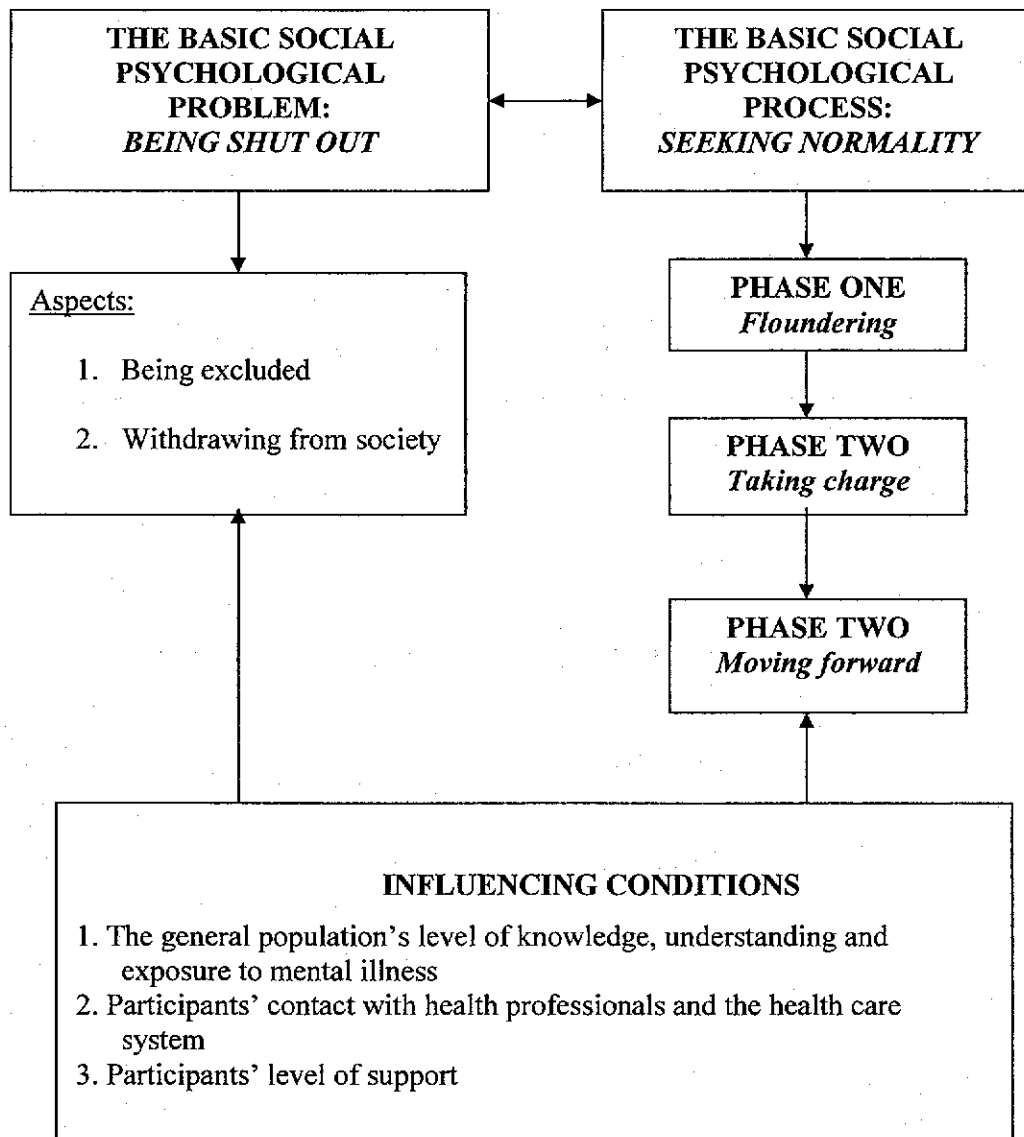
They tried to employ management practices to change their thinking and behaviour, so that they could engage in social activities and find a purpose in life. When their efforts failed they sought to educate themselves about their illness, contacting health professionals and self-help groups for assistance. However, these initial steps aimed at reducing their experience of *being shut out* were unsuccessful.

The second phase of the basic social psychological process of *seeking normality* was called *taking charge*. This phase consisted of two aspects: a *turning point* and *attitude change*. After *floundering* for many years, participants reached a *turning point*. For most participants, the *turning point* consisted of a significant personal crisis, which prompted drastic action to find a new direction in life. For some participants this meant leaving their hometown, family and jobs to get breathing space and to take stock of their lives. For other participants the *turning point* was a slow accumulation of disappointments over a longer period of time. They reacted to the *turning point* by changing aspects of their lives.

In this phase participants began to realise that they were able to improve their lives. The change in attitude was the foundation for entering the third phase of the basic social psychological process of *seeking normality*, which was called *moving forward*. This phase consisted of two aspects: *planning positive changes* and *taking practical steps*. In this phase participants devised plans to improve their lives and took practical steps to change their behaviour. They began to evaluate their behaviour, stopped using harmful substances and took medications that were beneficial to maintaining their health. They began to interact in society and to engage in social activities that other people took for granted. A welcome sign was when participants reported their suicidal thoughts had abated.

Three conditions were identified as influencing participants' experience of *being shut out* and *seeking normality*. The first condition was *the general population's level of knowledge, understanding and exposure to mental illness*. *Participants' contact with health professionals and the health system* was the second condition while the last condition was the *level of support* from family members, friends and groups in the community. In summary, the finding of *seeking normality* to overcome *being shut out* (see figure 3) saw participants move from a state of being isolated from the community they lived in towards one of becoming a valued member of society. The findings of this study will now be compared with existing research findings and theories surrounding the topic.

Figure 3: The finding of seeking normality to overcome being shut out



### **6.3: Comparison of the finding in this study of *seeking normality* to overcome *being shut out* with other research findings and theories**

The discussion outlines the similarities of relevant scientific literature with the finding of *seeking normality* to overcome *being shut out*. This comparison highlighted that many components of the findings in this study had been documented in existing literature but that the multi-dimensional experience of young adults living with a mental illness had not been presented previously. Several comparisons with studies on the experience of living with a mental illness will now be presented.

#### **6.3.1: A comparison of the finding in this study of *seeking normality* to overcome *being shut out* with Pickens (1999) "Living with a serious mental illness: The desire for normalcy"**

Pickens (1999) used Orem's Theory of Self-care as a framework to explore the life of 19 people with a serious mental illness aged between 19 and 64. 15 participants were hospitalised in a large psychiatric hospital and four were living in the community in North America. She found that the primary concern of participants in her study was the yearning for a normal life. These participants defined the concept of a normal life as "what is common and taken for granted ... by people who are not seriously mentally ill" (p. 233), and "having typical things and experiences [and] doing meaningful activity" (p. 236). Other meanings of normality reported by these participants were having relationships with family and friends, companionship, "learn to talk to someone" (p. 236), having a car, a house and household items, education and a better life. They also wanted to work, make the right decisions, better themselves and participate in the community or simply be "able to ride the bus alone and getting to the grocery store" (p. 236). Similar aspirations were also identified by participants in this study and were major components of the basic social psychological process of *seeking normality*.

Pickens (1999) also focused on her participants' self-care actions that promoted and maintained normality. Her participants wanted to "figure out what is wrong, study the illness, take medications, realize it is going to take time ... [and] accept the illness" (p. 237). These themes were reflected in the third phase of the basic social psychological process of *seeking normality* in this study. Participants in Pickens' (1999) study described the ways they managed emotional pain and distress. They reported that they "run away, sleep, do not dwell on it, try to brush it aside, hurt

self, try to fake everybody out [*sic*]/smile” (p. 237). In addition, they wanted to be well and get better by using similar strategies as participants in this study, such as eating well and socialising.

Pickens (1999) also identified what other people could do to help them with the promotion of normality, which was consistent with the first condition in this study, entitled *the general population's level of knowledge, understanding and exposure to mental illness*. Participants in both studies highlighted the importance of other people in “providing acceptance, understanding and support” (Pickens, p. 237). The literature search revealed that Pickens (1999) was the only author who identified the desire for normality as a central goal of people with a mental illness. Despite using different analytical frameworks, the findings of these two studies were very similar. This similarity is important and adds to the trustworthiness of the data of this study and demonstrates similar experiences of people with a mental disorder in other age groups and living in other social environments such as a mental health hospital.

### **6.3.2: A comparison of the finding in this study of *seeking normality* to overcome *being shut out* with Smith (2000) “Recovery from a severe psychiatric disability: Findings of a qualitative study”**

Smith (2002) conducted a grounded theory study with 10 people living in North America aged between 38 and 60 years who were recovering from schizophrenia, bipolar disorder and major depression. Concepts identified in Smith’s (2002) study closely resembled this current study, particularly the experience of a turning point. Participants in both studies reported experiencing a turning point as a result of a crisis and subsequently identified the importance of accepting that they had a mental illness and the need to make changes.

Smith (2002) also described critical factors that helped participants in her study to remain healthy. These findings corresponded to aspects in *moving forward*, the third phase of *seeking normality* in this study. Participants in Smith’s (2002) study reported that they were “struggling towards positive goals” (p. 150), taking “the right kinds of medication”, engaging in “meaningful activities”, having “a sense of control and independence”, “a strong desire to maintain recovery” and “a positive outlook on the present and the future” (p. 153). Smith (2002) also identified the importance of support from health professionals and friends to help participants in



her study maintain their recovery process, which was also mirrored in the second and third conditions in this study.

Although Smith's (2002) study shared many similarities with this study there were some differences. Smith (2002) explored her participants' experiences from the turning point onwards. She provided no detail of how participants managed their lives before the turning point although they stated that they had taken 10 to 15 years after the onset of their mental disorder to arrive at this point. In summary, the findings of Smith's (2002) study on recovery from a mental illness resembled many findings of this current study. The experience for both groups of participants described similar experiences of living with a mental illness even though the participants were from different countries and of different age groups. The consistency of findings between these two studies adds to the credibility and transferability of the findings of this study, along with the transferability of the findings to people with a mental illness in other age groups and living in other countries.

### **6.3.3: A comparison of the finding in this study of *seeking normality* to overcome *being shut out* with Neale (2000) "Suicidal intent in non-fatal illicit drug overdose"**

Neale's (2000) study examined the motivation to commit suicide of 38 Scottish patients, aged between 15 and 47 years, during admission to an accident and emergency department after a non-fatal drug overdose. Participants in her study wanted to commit suicide because of their inability to deal with problems and because "they had nothing to live for and no future" (p. 90). They also felt suicidal because of problems with family members or friends and their inability to get any help from health professionals and other services. These themes were similar to concepts identified by participants in this study in the basic social psychological process of *seeking normality* and in the second and third conditions.

In summary, the reasons given by participants in Neale's (2000) study for trying to commit suicide mirrored the suicidal thoughts of participants in this current study. The similarities are important and add to the trustworthiness of the data in this study and demonstrate similar experiences of people with a mental disorder in other Western countries.

**6.3.4: A comparison of the finding in this study of *seeking normality* to overcome *being shut out* with Hambrecht and Häfner (2000) “Cannabis, vulnerability, and onset of schizophrenia”**

The majority of participants in this study reported the use of illicit substances, including the use of marijuana, as important issues in their experience of living with a mental illness. Hambrecht and Häfner (2000) conducted a retrospective study using the framework of the vulnerability-stress-coping model to examine the relationship of the use of cannabis with the onset of psychosis in 232 German consumers. These authors found that prolonged use of cannabis contributed to the onset of symptoms in consumers who were vulnerable to developing a mental disorder because cannabis caused sub-acute brain damage (citing Castle & Ames, 1996). Hambrecht and Häfner (2000) also found that the use of cannabis increased consumers' level of stress and thereby precipitated the onset of their mental disorder. Participants in this current study attested to these findings in Hambrecht and Häfner's (2000) study. They reported how marijuana had contributed to the onset of their mental disorder in the first condition influencing the basic social psychological problem and process, entitled *the general populations' knowledge, understanding and exposure of mental disorders*, and described how substance use was an important feature in their inability to control their lives in the basic social psychological process of *seeking normality*.

Another group of consumers in Hambrecht and Häfner's (2000) study reported that they used cannabis as a means of coping with symptoms of their mental illness, called self-medication. This contrasted with the findings in this study, as participants did not use marijuana as a means of coping with their symptoms. In summary, the similarities and differences between Hambrecht and Häfner's (2000) study and the findings of this study add to the understanding of young adults' experience of living with a mental illness in rural Western Australia.

**6.3.5: A comparison of the findings in this study of *seeking normality* to overcome *being shut out* with Svedberg, Jormfeldt and Arvidsson (2003) “Patients' conceptions of how health processes are promoted in mental health nursing”**

Svedberg et al.'s (2003) phenomenographic study of 12 consumers living in a Swedish community identified how mental health nurses promoted good mental health in their clients. The nurses' attributes of showing trust, developing a feeling of

mutuality with consumers, being committed to good care, recognising consumers' right to self-determination and respect, and being accessible enhanced consumers' mental health. Consumers' level of mental health increased when they felt noticed, were hopeful, saw new possibilities, had their good qualities recognised, received education and were supported in their situation. These concepts were similar to those described by participants in this study and conceptualised in the second condition, entitled *participants' contact with health professionals and the health care system*.

In summary, both Svedberg et al.'s (2003) study and this current study emphasised the quality of the relationship between health professionals and consumers when participants were treated like valued human beings. The similarity between the two studies further adds to the trustworthiness of the findings of this study, particularly the extensive similarities in the second condition influencing the basic social psychological problem of *being shut out* and the basic social psychological process of *seeking normality*.

#### **6.3.6: A comparison of the finding in this study of *seeking normality* to overcome *being shut out* with the literature on rural mental health**

The literature dealing specifically with rural mental health issues in Australia has largely been written from health professionals' perspective. However, a review of this literature has been included to increase the understanding of young adults' experience of living with a mental illness in rural Western Australia. Issues brought up in the reviewed literature on rural mental health issues were geographical isolation (Fuller, Edwards, Proctor & Moss, 2000) and lack of access to specialist mental health services (Judd & Humphreys, 2001). Participants in this current study did not complain of geographical isolation and lack of access to services but reported that they did not get the right kind of help when they consulted health professionals, including psychiatrists.

Wainer and Chesters' (2000) study on mental health issues in rural Victoria highlighted some mental health risks associated with living in a rural area, for example, poverty, lack of education and employment opportunities, domestic violence and restrictions on the ability to express non-mainstream cultural beliefs. The authors claimed that social connectedness influenced a positive level of mental health. Participants in this current study did not speak of these issues.

Participants in Fuller et al.'s (2000) study who lived in rural South Australian reported that they did not seek out mental health services because of a culture of self-reliance, such as a "stiff upper lip" and the "mistrust of outsiders" (p. 151) as revealed in the quote: "I don't need any of that city-based crap" (p. 151). Again, this was not the attitude displayed by participants in this current study.

In summary, studies reviewed on rural mental health issues in Australia identified different concerns than those expressed by participants in this study. This may have occurred because the majority of participants had lived in other rural areas of Western Australia before moving to the study area following a turning point in their lives. Those participants who had always lived in the study area did so because of family support, which is fully described as the third condition influencing the problem and the process, entitled *participants' level of support*.

**6.3.7: A comparison of the findings in this study of *seeking normality* to overcome *being shut out* with Goffman (1968) "Stigma: Notes on the management of spoiled identity"**

An important feature in this current study was the stigma directed towards participants by society and their reaction to this stigma. Goffman (1968) defined stigma as "an undesired differentness" (p. 15) from what a normal person was expected to be and asserted that because of this difference the affected person was regarded as not quite human and so they were rejected and discriminated against. An important part of Goffman's (1968) theory was the realisation that the stigmatised person held the same views as other people about what was stigmatising. They applied the stigma to themselves and therefore displayed self-hatred and self-derogation. In a similar mode, participants in this study were stigmatised by other people and reported that they had attached stigma to others who had a mental illness in the basic social psychological problem of *being shut out*. Likewise, they regarded themselves as worthless and in need of punishment and reported low self-esteem and low self-confidence.

Goffman (1968) found that the affected individuals' response to being stigmatised could be two-fold. They either accepted that they had been stigmatised and embarked on the "moral career" (p. 45) of a person with stigma or they decided to conceal their differentness by avoiding contact with other people. Participants in this current study chose to conceal that they had a mental illness and withdrew from

contact with other people in the basic social psychological problem of *being shut out*. They rejected the possibility of pursuing the “moral career” of a person stigmatised by a mental illness by wanting to lead a normal life. In summary, there were many similarities between Goffman’s (1968) theory on stigma and the findings of this current study. These similarities confirm the transferability of some of the findings in this study to the experiences of people who have been stigmatised for reasons other than having a mental illness.

**6.3.8: A comparison of the finding in this study of *seeking normality* to overcome *being shut out* with Link, Struening, Dohrenwend, Cullen and Shrout’s (1989) modified labeling theory approach to mental disorders**

Many aspects of Link, Struening, et al.’s (1989) modified labeling theory were consistent with the findings in this current study. They stated that their theory of labelling and its effect on consumers was first proposed by Scheff in 1966 and subsequently modified by them. Understanding concepts related to labelling is important for consumers, health professionals and the public to avoid the negative consequences associated with labelling and to lessen its impact. Link, Struening, et al.’s (1989) modified labelling theory looked at the consequences of labelling rather than the processes leading to being labelled. Citing Scheff (1966, 1984) they explained that:

Once labeled, an individual is subject to uniform responses from others. Behaviour crystallizes in conformity to these expectations ... that constrain the labeled individual to the role of the “mentally ill person”. When the individual internalises this role, the process is complete (p. 402).

Link, Struening, et al.’s (1989) theory identified five steps to explain the consequences of being labeled. The first step was to be devalued and discriminated against. This “devaluation-discrimination” (p. 402) was internalised by people with a mental illness and, therefore, they expected to be rejected by others. This expectation happened as a result of socialisation and was not associated with the signs and symptoms of the mental disorder. Participants in this study supported the above supposition in the basic social psychological problem of *being shut out*. They were labeled as a person with a mental illness and expected others to reject them as they had internalised this label.

The second step in Link, Struening, et al.’s (1989) modified labeling theory explained that the label of being a person with a mental illness was acquired when

affected individuals entered treatment. The third step covered the response of people with a mental illness to being labeled. They saw the label as a threat and reacted to it by being secretive about their illness, by withdrawing from others, or by choosing to educate other people in the hope of changing their attitude. Educating others, however, involved disclosure and subsequent discrimination. In line with Link, Struening, et al.'s (1989) theory participants in this current study reacted to being labeled by trying not to disclose their mental illness to other people and by withdrawing from society. They only engaged in educating other people indirectly by taking part in this study and therefore maintained their anonymity.

The fourth step in the modified labeling theory explored the negative social consequences of being labeled. These consequences resulted either directly from the expectation of rejection and the belief that one was "set off from others and thus ... very different" (Link, Struening, et al., 1989, p. 403) resulting in subsequent low self-esteem, or indirectly from the response of secrecy and withdrawal, which, although protective, can "limit ... life chances" (p. 403) by reducing social networks and the search for job opportunities. Participants in this current study described their fear of being rejected because they were perceived as being different. They withdrew from interacting with other people and, therefore, limited their life chances.

Link, Struening, et al. (1989) looked at further consequences of being labeled in the fifth step, which suggested that the negative consequences of being labeled in step four could lead to a prolongation of the mental illness beyond its natural course. Link, Struening, et al. (1989) stated that if the label of being a person with a mental disorder was avoided, the negative social consequences would not occur and the person would be able to function better in society. Participants in this current study tried to escape being labeled and the associated negative consequences by wanting to be normal. In summary, Link, Struening, et al.'s (1989) modified labeling theory reflected many aspects of the finding of *seeking normality* to overcome *being shut out* and provided a systematic framework for explaining the experiences of participants in this study.

**6.3.9: A comparison of the finding in this study of *seeking normality* to overcome *being shut out* with Baxter and Diehl's (1998) model of emotional stages in recovering from the trauma of mental illness**

Baxter and Diehl's (1998) model of emotional stages of recovery was in many aspects similar to the findings in this study. It distinguished between three mental events occurring in the course of a mental illness, called "crisis", "decision" and "awakening" (p. 352). Consumers experienced a crisis when they were acutely ill, as a result of trauma or when they felt suicidal. Baxter and Diehl (1998) described consumers' reaction to a crisis as "denial, confusion, despair [and] anger" (p. 352). This reaction was similar to the first phase of the basic social psychological process of *seeking normality*, entitled *floundering*.

In the second emotional stage, called decision by Baxter and Diehl (1998), consumers might "make a decision to get going again" (p. 352). In this stage, consumers might strive to rebuild their lives by starting to take care of themselves and "to assume normal life roles" (p. 352). This corresponded to components in the second phase of the process in this current study, called *attitude change*.

Baxter and Diehl (1998) reported that in the third emotional stage, or awakening, consumers became aware of their "restructured personhood" (p. 352). They accepted what had happened, became confident in dealing with life, made plans to change their circumstances and wanted to help other people. They longed for close relationships with others and were looking for meaningful work. These aspects were also evident in participants' experience in this study, as described in the third phase of the process, identified as *moving forward*. In summary, the emotional stages of recovery model closely resembled the findings of this current study. The consistency of the findings of both the model and this study adds to the credibility and trustworthiness of the findings in this study.

**6.3.10: A comparison of the findings in this study of *seeking normality* to overcome *being shut out* with Marris' (1974) theory of loss and change**

Marris' (1974) founding theory of loss and change reflected several aspects of the findings of this study and an understanding of this theory adds to the understanding of participants' experience of what it was like to live with a mental illness. His theory stated that people made sense of their life by attaching meaning to relationships and events, which he called a "structure of meaning" (p. 4). The

structure of meaning provided a person with a purpose in life and shaped their identity. When the familiar pattern of life was disrupted by, for example, the death of a relative or social change, the affected individual experienced the loss of this structure of meaning and a "loss of self" (p. 33), which disrupted the "ability to organise experience in a meaningful way" (introduction, p. x). The more severe the loss the higher the disruption to a person's understanding of the "familiar assumptions about the world and one's place in it" (p. 151). Marris' (1974) theory of loss applied to the findings of this current study because having a mental illness caused severe disruption in participants' lives and as a result they experienced the loss of their identity as normal human beings and the loss of their standing in society or social identity, as described in the basic social psychological problem of *being shut out*. In line with this theory, they also lost the meaning and purpose in their life.

Marris (1974) recognised that a person's reaction to loss was very similar to the process of grieving traditionally identified as a reaction to the death of a loved one. Initially, the grieving person tried to ignore or avoid dealing with the disruptive event so as to protect their structure of meaning and their identity. In this state, people were disorientated and ambivalent about what they should do. They withdrew from relationships but at the same time, longed for company and support. They lingered in "aimless futility" (p. 25), which, according to Marris (1974), "sometimes leads to thoughts of suicide" (p. 25). This state of grieving culminated in a crisis originating from the loss of identity and the loss of meaning in life and the person was overwhelmed by feelings that their life was disintegrating. They were no longer able to understand what was happening and therefore could not see a future. In order to get through this crisis, the person had to reinterpret their identity and their place in the world. They achieved this by reworking the past and constructing new meaning, "repairing the thread of continuity" (p. 150) with their previous identity. Once this crisis had been worked through, the person regained "vitality and confidence for other purposes" (p. 149). These stages of grieving in Marris' (1974) theory reflected concepts in the social psychological process of *seeking normality* in this study.

Marris (1974) also explained how other people could help with the reinterpretation of meaning. They could help the grieving person by providing support and encouraging articulation of the experience. They could assist by offering companionship and by reassuring the person that what they were experiencing was natural and that a resolution of the crisis would be found in time. Other people,



however, could not reformulate the new structure of meaning for the affected person because only the grieving individual was able to find their own resolution. This component of Marris' (1974) theory mirrored aspects of the conditions influencing the social psychological problem of *being shut out* and the process of *seeking normality* in this current study.

In summary, many themes in Marris' (1974) theory of loss and change were identified in this study despite its emanation from a non-mental health framework. He showed that healthy people in other circumstances experienced aspects of the basic social psychological problem and process participants in this study engaged in. The similarities of the findings of this current study and Marris' (1974) theory are important and add to the trustworthiness of the data of this study.

#### **6.3.11: A comparison of the finding in this study of *seeking normality* to overcome *being shut out* with Parsons' (1951) concept of the sick role**

Parsons' (1951) founding work examined the social role of being sick, called "the sick role" (p. 436), and found that there was "a set of institutionalised expectations and the corresponding sentiments and sanctions" (p. 436) that applied to people who were ill. Participants in this study encountered the social expectations associated with being sick as identified in the first condition influencing the basic social psychological problem of *being shut out* and the process of *seeking normality*. Parsons (1951) identified four aspects of the social expectations of someone who was sick that applied to this condition. Firstly, according to Parsons (1951), sick individuals were exempted from their usual social responsibilities. This was dependent upon the medical condition being legitimised, usually by a doctor, and required that the sick person accepted that they were ill. Parsons (1951) ascertained that "this legitimation has the social function of protection against 'malingering'" (p. 437). The second aspect of the sick role, according to Parsons (1951), was society's acceptance that the sick person was unable to "pull himself together" (p. 437) on his own and needed help. The third aspect admonished the sick person to take the responsibility to get well and the fourth aspect dealt with the sick person's obligation to get competent help and to cooperate with prescribed treatment.

Participants in this current study fulfilled the obligations Parsons' (1951) sick role conferred on them by looking for competent help and cooperating with any reasonable treatment but found that society rejected the legitimation of mental

disorders and accused participants of being “bludgers” (P5). Participants were portrayed by other people as lying about their illness and as wanting to take advantage of their status as a person with a disability. In summary, Parsons’ (1951) concept of the sick role provided a useful framework for reflecting on aspects of participants’ experiences in this study.

**6.3.12: A comparison of the finding in this study of *seeking normality* to overcome *being shut out* with the medical model of treating people with a mental disorder**

Within the context of this study the researcher believed it was important to discuss the assumptions underlying the medical model of psychiatry and its relationship with the finding of *seeking normality* to overcome *being shut out*. Understanding the assumptions underlying the medical model and its impact on the treatment of people with a mental disorder in more detail is important for health professionals in order to help consumers more effectively.

Several authors explained the reason for the failure of the medical model of psychiatry to fully address the concerns of people with a mental disorder. The medical model is based on several assumptions, which shape its approach to treating people with mental disorders that have been challenged by Crowe (2000), Kruger (2000), and Kinderman and Cooke (2000). Crowe (2000), in her discourse analysis of the DSM-IV, pointed to the assumption in the medical model that mental disorders were solely the result of biochemical and physiological processes (citing Pardeck & Murphy, 1993) and that therefore external factors, such as social influences, that impacted on the person with a mental disorder, were ignored. Crowe (2000) explained that the identification of a disorder or diagnosis was more important in the medical model than dealing with the distress experienced as a result of social interaction. Egan et al. (2003), in their study on women’s accounts on their interactions with health practitioners in Victoria, Australia, found that health professionals “pathologised” (p. 30) their participants’ experience of mental illness whereas the participants saw their response to having a mental illness as “an appropriate response to a stressful environment” (p. 30), i.e. as a normal response. As a result of the assumption that mental disorders were solely brought on by biochemical and physiological processes the humanness of affected individuals and

their life experience was marginalised (Moyle, 2003) and feelings of despair were produced in consumers (Svedberg et al., 2003).

The findings of this current study supported the above critique of the medical model. Participants related their signs and symptoms in the context of their social world as “being excluded because of their behaviour” and as “being different” from other people in the basic social psychological problem of *being shut out*, and as being “unable to control” aspects of their lives in the basic social psychological process of *seeking normality*. The main concern common to all participants of *being shut out* from society was not found in the diagnostic categories of the DSM-IV-TR. Participants in this study did not want to be seen as pathological entities but as complete human beings. As a consequence of this divergent viewpoint of what it was like to live with a mental illness between participants and health professionals, participants reported that health professionals did not seem interested in what was happening to them and ignored their concerns, and therefore participants did not feel respected as human beings.

Kruger (2000) challenged another assumption of the medical model, i.e. that mental disorders were chronic conditions, using schizophrenia as an example. He gave three reasons for this assumption. He cited definitions of schizophrenia, found in the writings of Kraepelin (1912) and Bleuler (1924) that have historically included a chronic and deteriorating prognosis, called by Deegan (1997) a “prognosis of doom” (p. 16). The second reason, according to Kruger (2000), was that the DSM-IV adopted this assumption, which was then taught to health professionals as fact. The third reason given by Kruger (2000, citing Harding & Zahniser, 1994) was the “clinician’s illusion” (p. 31) where health professionals believed that their patients who were chronic sufferers were representative of all patients because they did not encounter many patients who had recovered from their illness. Kruger (2000) cited prospective longitudinal studies (Bleuler, 1978; Ciompi, 1980; Harding, Brooks, Ashikaga, Strauss & Breier, 1987; Huber, Gross & Linz, 1980; Tsuang, Woolsen & Fleming, 1979) that contradicted the belief that mental disorders were chronic conditions. These studies followed people with schizophrenia for two to six decades and found that over two-thirds had improved or recovered and were functioning well in society. The Australian survey on people living with psychotic illness (Jablensky, et al., 1999) also found that 60 % of individuals with psychotic disorders were satisfied with their level of independence. Kruger (2000) concluded that the

assumption of the medical model that mental disorders were chronic conditions condemned the ill person to “a lifetime of severe and unrelenting disability” (p. 30). He pointed out that as a result “the subjective experience of a catastrophic illness is worsened by the very psychiatric establishment that should be involved in the succor and healing of people” (p. 30). In support of Kruger’s (2000) critique, McCann (2002) found that participants in his study, conducted in Victoria, Australia, reacted to what they considered to be a potentially chronic illness by feeling so profoundly entrapped that they wanted to commit suicide.

Participants in this current study rejected the assumption of the medical model that the course of their mental disorder was chronic when they expressed their wish to lead a normal life. Similar to McCann’s (2002) study they also felt suicidal until they recognised that they were able to strive for normality and could escape the seeming permanence of their situation.

The third assumption of the medical model of psychiatry held that the diagnosis of a mental disorder was reliable and valid (Kinderman & Cooke, 2000). Participants in this current study complained that the diagnosis of their mental disorder had been highly unsatisfactory. Kinderman and Cooke (2000) found that the assumption that “particular psychological problems cluster together and can therefore be considered together” (p. 17) had not been proven. They asserted that diagnoses were neither reliable, in that clinicians often disagreed, nor valid, meaning that they were not scientifically meaningful, could not determine what treatments were likely to be effective and could not predict a course or outcome. In addition, treatment modalities advocated by the medical model such as medications and behavioural and cognitive therapy (Sadock & Sadock, 2003) helped some participants but were only used in the last phase of the basic social psychological process of “seeking normality”. The medical model does not address any of the other phases participants engaged in.

In summary, assumptions of the medical model of psychiatry were at variance with participants’ experience of living with a mental illness in rural Western Australia. The findings of this current study showed that this dichotomy explained some of the health professionals’ apparent incongruous attitudes and behaviours towards participants and leads the way to changing the treatment of people with a mental disorder.

**6.3.13: A comparison of the finding in this study of *seeking normality* to overcome *being shut out* with the paradigms of rehabilitation and recovery**

The researcher believed it was important to compare the paradigms of rehabilitation and recovery with the findings of this study because these paradigms have implications for the care of people with a mental disorder. Rehabilitation was defined as a “process through which a person is helped to adjust to the limitations of his disability” (Hume, 1994, p. 1), and its aim was to improve the quality of life (Sartorius, 2002) and to redress functional deficits (Flexer & Solomon, 1993, introduction, p. xiii). This definition indicated that the paradigm of rehabilitation when applied to people with a mental disorder was consistent with the medical model of psychiatry and its assumptions that mental disorders were regarded solely as pathologies occurring in chronic form. In support of this, Lunt (2000) pointed out that rehabilitation was “a concept of professionals about how to serve consumers ... [because] the structure of the questions, procedure, and process comes from professionals” (p. 402). Rehabilitation, however, differed from the medical model in that it sought to treat the consequences of the disorder and not just the signs and symptoms (Anthony, 1993). Its scope was broader because it addressed the concerns of the whole person and their social environment (Hume, 1994) and the client was treated as an “active, informed coequal participant” (Flexer & Solomon, 1993, introduction, p. xiv). These aims of rehabilitation, although still disease focused, were in partial agreement with what participants in this study expressed but would not have been sufficient to fulfill their main aim of *seeking normality*.

In contrast, the paradigm of recovery reflected the experience of participants in this study closely. Anthony (2000) reported that the empirical evidence for the paradigm of recovery was laid by studies mentioned above that proved that mental disorders were not necessarily chronic conditions and that recovery was possible. Anthony (1993) defined recovery in the following way:

Recovery is described as a deeply personal, unique process of changing one’s attitude, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness. (p. 15)

This vision of recovery was “incompatible” with the medical model (Anthony, 2000, p. 163) as it aimed for people with a mental illness to “grow beyond the limits of their condition and reclaim full lives” (Ridgway, 2001, p. 335). Tsai (2002), a consumer-writer, expressed this philosophy when she stated that she started on her road to recovery from mental illness not when she accepted that she was mentally ill but when she decided that she did not want to remain so. The experience of participants in this study, as described in the second and third phases of the basic social psychological process of *seeking normality*, was very similar to the paradigm of recovery.

In summary, the paradigm of rehabilitation did not address participants’ concerns adequately, whereas the paradigm of recovery reflected the reality of their experiences. As a result of this finding, health professionals need to pay close attention to the paradigm of recovery in order to more effectively help consumers overcome the negative aspects of living with a mental illness.

#### **6.3.14: Working collaboratively with consumers**

A major feature of the finding of *seeking normality* to overcome *being shut out* was the participants’ descriptions of their contact with health professionals. The majority of participants found that health professionals abused their power. Further exploration of power in the relationship with health professionals will add to the understanding of the experience of participants in this study. Honey (1999), in her grounded theory study on consumer participation in mental health services in Sydney, reported that the balance of power in the relationship between consumers and health professionals needed to shift from the power being entirely in the hands of health professionals towards empowering consumers. She defined empowerment as having a choice, making decisions, having responsibility and meaningful involvement. Consumers in her study wanted their concerns acknowledged and their suggestions acted on, and to receive information and feedback. Honey (1999) reported that although health professionals agreed with consumer empowerment, services had not changed, and she argued that consumer empowerment would only be implemented when consumers were allowed to exercise formal power. She explained that consumers would have formal power when their recommendations were binding and could not be overridden by health professionals in contrast to informal power where consumers could only use persuasion to present their point of

view to decision makers. This researcher suggests that formal power could be exercised in the framework of a partnership model, as advocated by Deegan (1992). Lammers and Happell (2003) defined partnership as a relationship where both consumers and health professionals “are valued as equal members of a team” (p. 391).

The Australian government recognised that formal partnerships needed to be set up in their policy documents such as the Second National Mental Health Plan (Australian Health Ministers, 1998) and reiterated in their National Mental Health Plan 2003-2008 (Australian Health Ministers, 2003). The Second National Mental Health Plan stated that it was imperative to “formally entrench partnership arrangements at both the system and service levels ... [with] consumers” (Australian Health Ministers, 1998, p. 16). However, the nature of these partnership models and the method of implementation were not detailed in the plans.

Shanley, Jubb and Latter (2003) proposed a partnership model for mental health nursing in Western Australia, called Partnership in Coping. The difficulties in devising a partnership model were shown by analysing this model and comparing it to the findings in this current study. These authors defined partnership as referring to “the relationship between two people working together to achieve a common goal” (p. 435) and by health professionals helping, negotiating and collaborating with the client. This model, however, did not address the power relationship between consumers and health professionals, which the participants in this current study highlighted as the most important aspect of their contact with health professionals. Shanley et al. (2003) also explained methods of coping to be employed by consumers in their model. Coping methods included “problem-focused forms of coping” (p. 435) such as “problem solving, conflict resolution, information gathering, advice seeking, time management and goal setting” (p. 435), and “emotion-focused forms of coping” (p. 435), which were described as “cognitive efforts that change the meaning of the situation without changing the environment through the use of techniques, for example, relaxation, meditation, exercise and the use of humor” (p. 435). Participants in this current study reported that they had used some of these coping methods with good effect but that they had played only a small part in their strategy to achieve normality.

In summary, the importance of addressing power concerns in the relationship between consumers and health professionals is well documented in the literature.

The Australian government advocated consumer empowerment and the development of partnership models but an appropriate model of implementation has still to be developed.

#### **6.3.15: Summary of the discussion**

The discussion focused on comparing the finding of *seeking normality* to overcome *being shut out* with other pertinent theories and research and found that many aspects of the experience of young adults living with a mental illness in rural Western Australia were encountered by consumers of other age groups and in other countries, and by many people not suffering from mental illness. The similarities of the reviewed literature and the findings in this study add to the credibility, trustworthiness, and transferability of the findings of this study. In addition, the comparison with existing literature also revealed that the findings in this study of *seeking normality* to overcome *being shut out* described the multidimensional experience of young adults living with a mental illness that had not previously been documented in the literature. The next section presents the implications and recommendations based on the findings of this study and the concluding statement.

#### **6.4: Implications of the findings**

This section of the thesis presents the applications of the finding of this study of *seeking normality* to overcome *being shut out*. The applications are described in terms of initiatives needed to help young adults living with a mental illness. It is suggested that these initiatives target the general population, media personnel, support groups, government policy planners and health professionals. Each of these initiatives will now be presented.

##### **6.4.1: Initiatives directed towards the general population**

Participants reported in the basic social psychological problem of *being shut out* that the general population excluded them from ordinary social activities due to stigma and stereotyping and subsequent discrimination. Therefore, there is a need for members of the general population such as friends, neighbours, acquaintances, teachers, and employers to increase friendly contact with young adults who have a mental illness as increased contact will reduce stigma and discrimination.



The general population should be encouraged to include this group of young adults in everyday activities. Davidson, Haglund, et al. (2001) showed in their study on supported socialisation that mundane acts such as sharing the shopping, going to the cinema or out for a cup of tea or a meal with someone with a mental illness affirmed to them that they were seen as worthwhile human beings. According to Davidson, Stayner, et al. (2001) this acknowledgement provided a sense that life could be enjoyable and hope that they could escape the "big horror" (p. 275) of living with a mental illness. If young adults with a mental illness do not want to go out, friends, neighbours and acquaintances should drop by to indicate their willingness to provide companionship.

School teachers can help to reduce the occurrence of stigma and stereotyping of young consumers by emphasising in their early education programmes that any person with a disability including people with a mental disability are the same on a human level and that the disability is only a superficial occurrence and should not distract from the need to be included in everyday activities. School programmes aimed at positively influencing the perception of what it is like to live with a mental illness will prevent or reduce school children from developing stereotypical images of people with a mental disorder. Spitzer and Cameron (1995) showed in their study on school-age children's perceptions of mental illness that children were affected by images of consumers on television and in films. Therefore, emphasis in school curricula on a realistic and empathetic depiction of what it is like to live with a mental illness would be effective. In addition, participants in this current study reported that they left school after year 10 because they were not fit for the school environment. It is, therefore, recommended that teachers should develop programmes to suit this group of students so that they are able to stay at school after year 10 and fulfill their intellectual and vocational potential. In addition, students with mental health issues and their parents should work with appropriately educated school health nurses and school psychologists to facilitate diagnosis and treatment of mental disorders to enhance the students' educational outcomes.

Participants pointed out the advantages of employment and it is, therefore, recommended that young adults with a mental illness should be retained in the workforce. The employment environment should be adapted to their needs as has been successfully done for people with a physical disability. Davidson, Stayner, et al. (2001) stated that ways had been found to "restore varying degrees of normality to

the lives of people who are blind, deaf, or paraplegic ... despite their deficit or disorders" (p. 377), and that it had to be accepted that there were some things people with mental disorders would not be able to do. Employers should, therefore, consult young adults living with a mental illness to negotiate employment opportunities suitable for them. The Australian government is also providing assistance to employers with paying wages if there is an additional cost of employing a person with a disability and is providing help for people to keep their job if their employment is in jeopardy due to a disability (Centrelink, 2004).

In summary, the general population represented by friends, neighbours, acquaintances, teachers and employers can provide practical measures to reduce the isolation of young adults living with a mental illness in rural Western Australia and facilitate their movement towards living a normal life.

#### **6.4.2: Initiatives directed towards media personnel**

Participants reported that the general population was scared to meet them as the media had influenced the negative attitude of the public towards them. Link, Phelan, et al. (1999) concurred that the public was frightened of the possibility that some consumers could be violent. This fear of meeting consumers was increased because the media "routinely stigmatized" (Philo, 1996, introduction, p. xi) and sensationalised (Hazelton, 1997) the small number of violent events where consumers were involved and therefore "distort[ed] public perceptions" (Philo, 1996, introduction, p. xii). The Australian government, in its National Mental Health Plan 2003-2008, recognised the important influence of the media and has called for the "promotion of accurate portrayal of mental health problems and mental illness in the media" (Australian Health Ministers, 2003, p. 17). Therefore the media, especially television (Secker, Armstrong & Hill, 1999) and cinema, should portray people with a mental illness in an empathetic and realistic light. In order to reach a wide audience, soap operas and popular talk shows should include characters and people who are successfully living with a mental illness. However, changing the way the media portrays people with a mental illness is a complex topic (Anderson, 2003; Hazelton, 1997; Philo, 1996) and therefore the initiatives directed towards media personnel need much further exploration. In summary, the media are an influential medium and should use their influence to change the general population's attitude

towards mental health issues and thereby help improve the lives of young adults with a mental illness.

#### **6.4.3: Initiatives directed towards support groups in the community**

Participants accessed support groups offering services to the general population but shunned groups focusing solely on serving people with a mental disorder because of the stigma associated with these groups. Other authors also found that consumers rejected services set up especially for them. Participants in their studies did not want separate daycare facilities (Shephard et al., 1995), counseling services at university (Megivern et al, 2003) or congregated housing built for consumers (Warren & Bell, 2000). Support groups therefore should be part of mainstream organisations used by the general population so that they are not identified with the mental health label and rejected by young adults with a mental illness. In summary, support groups provide an important service and should be located where consumers will access them.

#### **6.4.4: Initiatives directed towards government policy planners**

Participants reported that they did not want to use mental health hospitals or health services existing exclusively for consumers because of the attached stigma. They were, however, happy with being admitted to general hospitals and using services of health professionals catering for the general population. This integration of services for consumers with those for the general population should be further developed and expanded. The Australian government already spearheaded the integration of mental health services with services for the general population in their National Mental Health Policy 1992 (Australian Health Ministers Conference, 1992). This policy has resulted in the closure of many stand-alone psychiatric hospital beds and the opening of beds for people with a mental disorder in general hospitals (Australian Health Ministers, 1998). Further integration of health services can be achieved by closing stand alone mental health services such as community mental health and combining them with other services readily accessed by young consumers. For example, Sweeney and Kisely (2003) recommended in their study on community-care and mental health workers' views on the barriers to the management of mental health problems in Esperance, a rural center in Western Australia, that mental health services should be amalgamated with generalist

community health. Summers and Happell (2003) also recommended that the existing generalist services should be broadened by the inclusion of mental health nurses working in general hospital settings and that discrete psychiatric services should be avoided. However, they found in their study on consumers' satisfaction with services provided in an emergency department in Melbourne that consumers encountered negative attitudes of general nursing staff, such as inappropriate treatment and comments, and preferred to be treated by specialist mental health nurses. Sharrock and Happell (2002) uncovered that the reason for the general nurses' negative attitude was their perception that they did not have the required skills, confidence or knowledge to care adequately for patients with mental disorders. They therefore supported the introduction of a psychiatric consultation-liaison nurse's position into general hospitals so that specialist mental health nurses work alongside general nurses and educate and support them on the care of consumers. A psychiatric consultation-liaison nurse's position has been created in the local hospital of the study area and it is hoped that it will be as successful as the one in Melbourne (Sharrock & Happell, 2002).

With regards to treatment modalities the findings of this study support the paradigm of recovery. The Australian government recognised that "a recovery orientation should drive service delivery" (Australian Health Ministers, 2003, p. 11). Anthony (2000) suggested standards for a recovery oriented mental health system that were compatible with the principles of the recovery paradigm. These standards should include services such as medical treatment of symptoms and alleviating distress, crisis intervention to assure the consumers' personal safety, case management to obtain the services the consumer required, rehabilitation to restore role functioning, and consumer enrichment programmes to promote self-development by finding fulfilling and satisfying activities. These standards also comprised rights protection to attain equal opportunities, basic support to secure housing, food and health care, self-help programmes to facilitate empowerment, and working towards wellness and prevention to promote a healthy lifestyle (Anthony, 2000). It is recommended that these standards should be adapted to the care of young consumers living in rural Western Australia.

In summary, formal health care services for young adults with a mental illness should be fully integrated with services for the general population so that this group of consumers readily accesses them. In addition, standards for a recovery

oriented mental health system should be adopted so that the needs of young adults with mental disorders are met.

#### **6.4.5: Initiatives directed towards health professionals**

Initiatives directed towards health professionals could also reduce the isolation of young adults with a mental illness and facilitate their goal of *seeking normality*. Health professionals and their organisations can improve the lives of young adults with a mental illness with regards to stigmatisation, the quality of contact with health services, education of health professionals and treatment modalities. Stigma was a major issue reported by participants and it is, therefore, recommended that professional organisations design and implement stigma reduction programs. Health professionals should not restrict their professional activities to the treatment of consumers but address stigma as a separate factor (Link, Struening, et al., 1987) in order to address the hostility people with a mental illness encounter in the community (Rosenfield, 1997). Rosenfield (1997) found in her study on the effect of stigma on consumers' life satisfaction that "the best [medical] treatment given by the people with the best intentions is not enough, because the treatment has little power to decrease stigma" (p. 670). Stigma reduction of mental disorders is possible, as it was achieved with physical disabilities. Davidson, Stayner, et al. (2001) gave an example of the past stigmatisation of people with blindness, which was associated with "profound disability, unemployment, poverty, and marginalization" (p. 368). According to Davidson, Stayner, et al. (2001) blind individuals were portrayed as "disheveled, malnourished people wearing dark glasses, selling pencils in front of the post office" (p. 368). They pointed out that now it was "more appropriate to consider examples of blindness to be Ray Charles, Stevie Wonder, or Jose Feliciano. Of these people we might say that they just happen to be blind" (p. 368). They hoped that in the future mental illness would be seen as "divorced from poverty, oppression, and marginalization and will be considered something that 'just happens' to people" (p. 368). They ascertained that people with mental disorders should be regarded as being "primarily other things like musicians, writers, or friends" (p. 368).

Health professionals should also improve the quality of contact of health services with young consumers. Participants stated that they withdrew from health services when they were treated with disrespect and were seen as inferior by health

professionals. Implementing a formal partnership model can ensure that health professionals treat young adults with a mental disorder as valued human beings and involve them in treatment programmes as active participants despite their illness (Deegan, 1997). The Australian government highlighted the importance of consumer participation and partnership "at all levels of policy, planning and treatment" (Australian Health Ministers, 2003, p. 24). It is, therefore, recommended that health professionals develop and implement a formal partnership model.

Participants spoke of the need for the education of health professionals to improve health professionals' knowledge of what it is like to live with a mental illness and increase their willingness and ability to help consumers. Education, therefore, should include research findings on young adults' experience of living with a mental illness. The importance of incorporating consumer-driven materials in the education of health professionals was recognised by the Deakin Human Services Australia (1999) in their report on Education and Training Partnerships in Mental Health funded by the National Mental Health Strategy. Therefore, it is recommended that education programmes for health professionals should include awareness of what is like to live with a mental illness from the young consumer's perspective based on research.

Health professionals can improve the treatment of young adults with a mental illness further by adopting the principles of the recovery paradigm. Health professionals need to understand that they can facilitate the recovery process in consumers by "believ[ing] in and stand[ing] by the person in need of recovery" (Anthony, 1993, p. 18) and instill hope in consumers (McCann, 2002) that recovery is possible. Health professionals need to realise that recovery from mental illness can occur even when symptoms are still present but the frequency and duration of symptoms will be reduced (Anthony, 1993). Health professionals need to be aware of the benefits for consumers of utilising the recovery process such as increased self-efficacy, better community living skills, improved self-esteem, a feeling of empowerment and a positive attitude towards improving their health (Bullock, Ensing, Alloy & Weddle, 2000). In addition, health professionals need to enlighten consumers that many of their responses to being mentally ill are normal and not part of the mental disorder (Anthony, 1993).

In summary, it is recommended that health professionals should broaden their treatment of young adults living with a mental illness in order to provide them with

effective help. They should address the stigma faced by consumers, implement formal partnership models, entrench the perspective of consumers in the education of health professionals and include the paradigm of recovery in their practice.

#### 6.4.6: Initiatives directed towards nurses

Participants attested to the importance of nurses as case managers and primary health care professionals caring for young adults living with a mental illness. Therefore, nurses should ensure that they address the main concerns of their clients, which has been shown by this study to be isolation and the quest to lead a normal life. Nurses should reach out and spend quality time with their clients to show them that they have not been abandoned. In order to combat the stigma and hostility of the general population directed against young adults with a mental illness, nurses should implement the stigma reduction programmes developed by professional health organisations and educate people in their communities. Furthermore, with the permission of their patients, nurses should try and set up a network of friends, neighbours and volunteers who are willing to visit young adults with a mental illness.

It is also recommended that nurses should be aware of the importance of the quality of their relationship with young consumers. Nurses should move away from their technique of subtle coercion (Lützn, 1998) to facilitate the empowerment (Tilley, Pollock & Tait, 1999) and self-determination (McCann & Clark, 2004) of young adults. Jackson and Stevenson (2000) stated that nurses need to learn to “care about” their patients and not “care for” them as “caring for” implies “dominance of the carer and disempowerment of the cared for” (Swaan, 1990, cited in Jackson & Stevenson, 2000, p. 383). Caring, according to Hörberg et al. (2004), means trying to “understand how a client/patient experiences his/her life situation” (p. 16).

It is recommended that nurses take the initiative to improve the services for young adults living with a mental illness within the recovery framework. In order to develop, adapt and implement the paradigm of recovery nurses should develop a new assessment format based on the basic social psychological process of *seeking normality* in this study and tailor their interventions according to the needs of their clients in each phase. They should be observant as to their clients’ transition from one phase to the next and facilitate this transition. In the first aspect of phase one of the basic social psychological process, identified as *avoidance behaviours*, nurses

should, according to Moyle (2003), provide comfort, safety and security and show their support by “being with the patient ... [and] offer reassurance and belief in the patient’s ability to rise out of the despair [of their mental illness]” (p. 105). When young adults experience the second aspect of phase one, entitled *trying to make changes*, nurses should provide education about the relevant mental disorder and the treatment options. In the second phase, when young adults experience a personal crisis such as a suicide attempt, nurses should facilitate their clients’ resolution of the crisis and their movement towards an *attitude change*. Aoun and Johnson (2001) found in their study on consumers’ perspective of a suicide intervention programme in Bunbury, Western Australia, that a high intensity approach to suicide intervention improved consumers’ ability to deal with problems. Once young adults with a mental illness experience an *attitude change*, nurses should encourage them to plan for and take practical steps in normalising their lives as described in the third phase of the basic social psychological process of *seeking normality*, entitled *moving forward*.

Edwards (2000) recommended that if nurses were not able to change the response of the health care system to the needs of consumers, a new service should be set up to deliver effective care. This service should operate outside the medical model with “new structures of responsibility, accountability and control” (p. 564) with a new type of health care professional who is responsive to the needs of consumers. One such programme, the “BRIDGES (Building Recovery of Individual Dreams and Goals through Education and Support): A journey of hope” programme developed by the Tennessee Alliance for the Mentally Ill and the Tennessee Mental Health Consumers’ Association and based on the emotional stages of recovery has been developed, and is run by consumers without the input from health professionals (Baxter & Diehl, 1998).

In summary, nurses should spearhead the attitude change of the general population to reduce the stigma and discrimination in the community. They should be politically active to put pressure on policy planners to implement the policy changes necessary to improve services for young adults living with a mental illness. They should be at the forefront of improving the effectiveness of the health care system to meet the needs of young consumers by thinking outside the medical model of psychiatry and devising and implementing strategies based on research.



### 6.5: Limitations of the study

Self selected, motivated young adults from an Anglo-Saxon background with a variety of psychiatric disorders who agreed to speak about their experience were interviewed for this study. As the homogeneous cultural backgrounds of participants could be viewed as a limitation of the study generalisations about the findings should be made with caution. However, the diversity of categories that emerged from the data and their linkages to the core category clearly ensured that all aspects of young adults' experience of living with a mental illness were represented and categories were expansive and saturated. Further research in this area could focus on diagnostic specific groups of consumers to identify differences in experiences across these groups.

### 6.6: Further research

The findings of this study uncovered the multidimensional aspects of young adults' experiences of living with a mental illness in rural Western Australia. The finding of *seeking normality* to overcome *being shut out* revealed the basic social psychological problem experienced by young adults with a mental illness and the process they engaged in to overcome this problem. While the findings of this current study add to the existing literature, further research is needed to fully understand the phenomenon of living with a mental illness. This research needs to focus on the experience of consumers who are older than 30 years and on the issues of suicide, the use of illicit substances and the experience of hallucinations and delusions. It is also recommended that further research be conducted on the assessment and care of consumers based on the findings of this study and focus on the development of a recovery model suitable to consumers in Australia and the evaluation of its implementation. Finally, further research is needed to evaluate the effectiveness of national anti-stigma programmes and education sessions in schools to increase the general public's understanding of what it is like to live with a mental illness.

### 6.7: Concluding statement

The objectives of this study were to explore and explain young adults' experience of living with a mental illness in rural Western Australia and to identify factors impacting on that experience. The use of the grounded theory method

allowed the identification of a basic social psychological problem and a basic social psychological process, which was shared by the participants.

Participants felt *being shut out* when they were rejected by other people because they had a mental illness and because of their behaviour. Participants were not included in social activities and were discriminated against. Participants withdrew from other people when they realised that they were different and that this scared them. As a result of *being shut out* participants did not mix with other people and stayed at home. *Seeking normality* was a process that participants engaged in to again become part of ordinary social life in the community. The experience of *seeking normality* consisted of a three-phase process. Phase one occurred predominantly in the time before the experience of a turning point, and participants engaged in the remaining two phases when they had realised that they could take charge of their lives and make positive changes to their life in order to become valued members of society. Three conditions influenced the basic social psychological problem and process. These were *the general populations' understanding, knowledge and exposure to mental illness, participants' contact with health professionals and the health care system* and the *participants' level of support* from family members, friends and groups in the community.

The findings of this study will be of value to young adults living with a mental illness, the general population and media personnel, health professionals, government policy planners and support groups. The findings can be used in a variety of ways to facilitate young adults' movement from *being shut out* through the process of *seeking normality*.

In conclusion, I feel honored that participants gave me their time to tell me their story. I have gained great respect for their insight, courage and strength to cope with life with a mental illness and have become committed to promoting the cause of young adults living with a mental illness and to disseminate the findings so that their voice can be heard. I feel that my professional and personal life has been greatly enhanced as a result of this study.

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## APPENDIX A

### Diagnostic and statistical manual of the American Psychiatric Association classification of disorders (DSM-IV-TR)

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The DSM-IV-TR is comprised of a multi axial assessment system. The five axes included in the DSM-IV-TR multiaxial classification system are:

Axis I	Clinical disorders, other conditions that may be a focus of clinical attention
Axis II	Personality disorders, mental retardation
Axis III	General medical conditions
Axis IV	Psychosocial and environmental problems
Axis V	Global assessment of functioning

The use of the multiaxial system facilitates comprehensive and systematic evaluation with attention to the various mental disorders and general medical conditions, psychosocial and environmental problems, and level of functioning that might be overlooked if the focus were on assessing a single presenting problem. (p. 27)

#### *Mood disorders*

#### *The DSM-IV-TR diagnostic criteria for Major Depressive Disorder*

- A. Five (or more) of the following symptoms have been present during the same 2 week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.
1. Depressed mood for most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful)  
**Note:** In children and adolescents, can be irritable mood
  2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation made by others)
  3. Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day  
**Note:** In children, consider failure to make expected weight gains.
  4. Insomnia or hypersomnia nearly every day
  5. Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down)
  6. Fatigue or loss of energy nearly every day
  7. Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick)

8. Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others)
  9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide
- B. The symptoms do not meet criteria for a Mixed Episode.
- C. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- D. The symptoms are not due to the direct physiological effects of a substance (e.g. a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).
- E. The symptoms are not better accounted for by Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than two months or are characterised by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation. (p. 356)

*DSM-IV-TR diagnostic criteria for dysthymic disorder*

- A. Depressed mood for most of the day, for more days than not, as indicated either by subjective account or observation by others, for at least two years. Note: In children and adolescents, mood can be irritable and duration must be at least one year.
- B. Presence, while depressed, of two (or more) of the following:
1. Poor appetite or overeating
  2. Insomnia or hypersomnia
  3. Low energy or fatigue
  4. Low self-esteem
  5. Poor concentration or difficulty making decisions
  6. Feelings of hopelessness
- C. During the two-year period (one year for children or adolescents) of the disturbance, the person has never been without the symptoms in Criteria A and B for more than 2 months at a time.
- D. No major Depressive Episode has been present during the first two years of the disturbance (one year for children and adolescents); i.e., the disturbance is not better accounted for by chronic Major Depressive Disorder, or Major Depressive Disorder, In Partial Remission.

**Note:** There may have been a previous Major Depressive Episode provided there was a full remission (no significance signs or symptoms for two months) before development of the Dysthymic Disorder. In addition, after the initial two years

(one year in children or adolescence) of Dysthymic Disorder, there may be superimposed episodes of Major Depressive Disorder, in which case both diagnoses may be given when the criteria are met for a Major Depressive Episode).

- E. There has never been a Manic Episode, a Mixed Episode, or a Hypomanic Episode, and criteria have never been met for Cyclothymic Disorder.
- F. The disturbance does not occur exclusively during the course of a chronic Psychotic Disorder, such as Schizophrenia or Delusional Disorder.
- G. The symptoms are not due to the direct physiological effects of a substance (e.g. a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).
- H. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning. (pp. 380-381)

***DSM-IV-TR Diagnostic Criteria for Manic and Hypomanic Episodes***

*Manic episode*

- A. A distinct period of abnormally and persistently elevated, expansive, or irritable mood, lasting at least one week (or any duration if hospitalisation is necessary).
- B. During the period of mood disturbance, three (or more) of the following symptoms have persisted (four if the mood is only irritable) and have been present to a significant degree:
  1. Inflated self-esteem or grandiosity
  2. Decreased need for sleep (e.g., feels rested after only 3 hours of sleep)
  3. More talkative than usual or pressure to keep talking
  4. Flight of ideas or subjective experience that thoughts are racing
  5. Distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli)
  6. Increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation
  7. Excessive involvement in pleasurable activities that have a high potential for painful consequences (e.g., engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments)
- C. The symptoms do not meet criteria for Mixed Episode.
- D. The mood disturbance is sufficiently severe to cause marked impairment in occupational functioning or in usual social activities or relationships with others, or to necessitate hospitalisation to prevent harm to self or others, or there are psychotic features.

- E. The symptoms are not due to the direct physiological effects of a substance (e.g. a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).

**Note:** Manic- like episodes that are clearly caused by somatic antidepressant treatment (e.g. medications, electroconvulsive therapy, light therapy) should not count toward a diagnosis of Bipolar I Disorder. (p. 362)

*Hypomanic episode*

- A. A distinct period of persistently elevated, expansive, or irritable mood, lasting at least four days, that is clearly different from the usual non-depressed mood.
- B. [Same mood disturbances as in Manic Episode occur.]
- C. The episode is associated with an unequivocal change in functioning that is uncharacteristic of the person when not symptomatic.
- D. The disturbance in mood and the change in functioning are observable by others.
- E. The episode is not severe enough to cause marked impairment in social or occupational functioning, or to necessitate hospitalization, and there are no psychotic features.
- F. The symptoms are not due to the direct physiological effects of a substance (e.g. a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).

**Note:** Manic- like episodes that are clearly caused by somatic antidepressant treatment (e.g. medications, electroconvulsive therapy, light therapy) should not count toward a diagnosis of Bipolar I Disorder. (p. 368)

***DSM-IV-TR Diagnostic Criteria for Bipolar I Disorder Variants***

*Bipolar I disorder, single manic episode*

- A. Presence of only one Manic Episode and no past Major Depressive Episodes

**Note:** Recurrence is defined as either a change in polarity from depression or an interval of at least two months without manic symptoms.

- B. The Manic Episode is not better accounted for by Schizoaffective Disorder and is not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.

*Bipolar I episode, most recent episode hypomanic*

- A. Currently (or most recently) in a Hypomanic Episode.

- B. There has previously been at least one Manic Episode or Mixed Episode.
- C. The mood symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- D. The mood episodes in Criteria A and B are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.

*Bipolar I episode, most recent episode manic*

- A. Currently (or most recently) in a Manic Episode.
- B. There has previously been at least one Major Depressive Episode, Manic Episode, or Mixed Episode.
- C. The mood episodes in Criteria A and B are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.

*Bipolar I episode, most recent episode mixed*

- A. Currently (or most recently) in a Mixed Episode.
- B. There has previously been at least one Major Depressive Episode, Manic Episode or Mixed Episode.
- C. The mood episodes in Criteria A and B are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.

*Bipolar I episode, most recent episode depressed*

- A. Currently (or most recently) in a Major Depressive Episode.
- B. There has previously been at least one Manic Episode or Mixed Episode.
- C. The mood episodes in Criteria A and B are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified. (pp. 388-391)

***DSM-IV-TR criteria for Bipolar II disorder***

- A. Presence (or history) of one or more Major Depressive Episodes.

- B. Presence (or history) of at least one Hypomanic Episode.
- C. There has never been a Manic Episode or a Mixed Episode.
- D. The mood episodes in Criteria A and B are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.
- E. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning. (p. 397)

***DSM-IV-TR Diagnostic Criteria for Cyclothymic Disorder***

- A. For at least 2 years, the presence of numerous periods of hypomanic symptoms and numerous periods with depressive symptoms that do not meet criteria for a Major Depressive Episode.  
 Note: In children and adolescents, the duration must be at least 1 year.
- B. During the above 2-year period (1 year in children and adolescents), the person has not been without the symptoms in Criterion A for more than 2 months at a time.
- C. No Major Depressive Episode, Manic Episode, or Mixed Episode has been present during the first 2 years of the disturbance.  
 Note: after the initial 2 years (1 year in children and adolescents) of Cyclothymic disorder, there may be superimposed Manic or Mixed Episodes (in which case both Bipolar I Disorder and Cyclothymic Disorder may be diagnosed) or Major Depressive Episodes (in which case both Bipolar II and Cyclothymic Disorder may be diagnosed).
- D. The mood episodes in Criteria A are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.
- E. The symptoms are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).
- F. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning. (p. 400)

***Schizophrenia***

***DSM-IV-TR diagnostic criteria for schizophrenia***

- A. Characteristic symptoms: Two (or more) of the following, each present for a significant portion of the time during a 1-month period (or less if successfully treated):



1. Delusions
2. Hallucinations
3. Disorganised speech (e.g. frequent derailment or incoherence)
4. Grossly disorganised or catatonic behaviour
5. Negative symptoms, i.e., affective flattening, alogia, or avolition.

**Note:** Only one Criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behaviour or thoughts, or two or more voices conversing with each other.

- B. *Social/occupational dysfunction:* For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning, such as work, interpersonal relations, or self care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).
- C. *Duration:* Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meet Criterion A (i.e., active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).
- D. *Schizoaffective and Mood disorder exclusion:* Schizoaffective Disorder and Mood Disorder With Psychotic Features have been ruled out because either (1) no Major Depressive, Manic, or Mixed Episodes have occurred concurrently with the active-phase symptoms; or (2) if mood episodes have occurred during active-phase symptoms their total duration has been brief relative to the duration of the active and residual periods.
- E. *Substance/general medical condition exclusion:* The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.
- F. *Relationship to a Pervasive Development Disorder:* If there is a history of Autistic Disorder or another Pervasive Development Disorder, the additional diagnosis of Schizophrenia is only made if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated). (p. 312)

#### *Schizophreniform Disorder*

Criteria A, D and E of Schizophrenia are met.

An episode of the disorder (including prodromal, active, and residual phases) lasts at least 1 month but less than 6 months. (When the diagnosis must be made without waiting for recovery, it should be qualified as "Provisional".) (p. 319)

*Schizoaffective Disorder*

- A. An uninterrupted period of illness during which, at some time, there is either a Major Depressive Episode, a Manic Episode, or a Mixed Episode concurrent with symptoms that meet Criterion A for Schizophrenia.

**Note:** The Major Depressive Episode must include Criterion A1: depressed mood.

- B. During the same period of illness, there have been delusions or hallucinations for at least 2 weeks in the absence of prominent mood symptoms.
- C. Symptoms that meet criteria for a mood episode are present for a substantial portion of the total duration of the active and residual periods of the illness.
- D. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition. (p. 323)

*Anxiety disorders*

***DSM-IV-TR general diagnostic criteria for panic attack***

**Note:** A Panic Attack is not a codable disorder. Code the specific diagnosis in which the Panic Attack occurs.

A discrete period of intense fear or discomfort, in which four (or more) of the following symptoms developed abruptly and reached a peak within 10 minutes:

1. Palpitations, pounding heart, or accelerated heart rate
1. Sweating
2. Trembling or shaking
3. Sensations of shortness of breath or smothering
4. Feeling of choking
5. Chest pain or discomfort
6. Nausea or abdominal distress
7. Feeling of dizziness, unsteady, light headed, or faint
8. Derealization (feelings of unreality) or depersonalisation (being detached from oneself)
9. Fear of losing control or going crazy
10. Fear of dying
11. Paresthesias (numbness or tingling sensation)
12. Chills or hot flushes (p. 432)

***DSM-IV-TR general diagnostic criteria for agoraphobia***

**Note:** Agoraphobia is not a codable disorder. Code the specific diagnosis in which the Agoraphobia occurs.

- A. Anxiety about being in places or situations from which escape might be difficult (or embarrassing) or in which help may not be available in the event of having an unexpected or situationally predisposed Panic Attack or panic-like symptoms.

Agoraphobic fears typically involve characteristic clusters of situations that include being outside the home alone; being in a crowd or standing in a line; being on a bridge; and traveling in a bus, train, or automobile.

**Note:** Consider the diagnosis of Specific Phobia if the avoidance is limited to one or only few specific situations, or Social Phobia if the avoidance is limited to social situations.

- B. The situations are avoidable (e.g., travel is restricted) or else are endured with marked distress or with anxiety about having a Panic Attack or panic-like symptoms, or require the presence of a companion.
- C. The anxiety or phobia is not better accounted for by another mental disorder, such as Social Phobia (e.g., avoidance limited to social situations because of fear of embarrassment), Specific Phobia (e.g., avoidance limited to a single situation like elevators), Obsessive-Compulsive Disorder (e.g., avoidance of dirt in someone with an obsession about contamination), Posttraumatic Distress Disorder (e.g., avoidance of stimuli associated with a severe stressor), or Separation Anxiety Disorder (e.g., avoidance of leaving home or relatives). (p. 433)

***DSM-IV-TR general diagnostic criteria for panic attack with agoraphobia***

- A. Both (1) and (2):
  - 1. Recurrent unexpected Panic Attacks
  - 2. At least one of the attacks has been followed by 1 month (or more) of one (or more) of the following:
    - a) Persistent concern about having additional attacks
    - b) Worry about the implications of the attack or its consequences (e.g., losing control, having a heart attack, "going crazy")
    - c) A significant change in behaviour related to the attacks
- B. The presence of Agoraphobia.
- C. The Panic Attacks are not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., hyperthyroidism)
- D. The Panic Attacks are not better accounted for by another mental disorder, such as Social Phobia (e.g., avoidance limited to social situations because of fear of embarrassment), Specific Phobia (e.g., avoidance limited to a single situation like elevators), Obsessive-Compulsive Disorder (e.g., avoidance of dirt in someone with an obsession about contamination), Posttraumatic Distress Disorder (e.g., avoidance of stimuli associated with a severe stressor), or Separation Anxiety Disorder (e.g., avoidance of leaving home or relatives). (p. 441)

***DSM-IV-TR general diagnostic criteria for substance dependence***

A maladaptive pattern of substance use, leading to clinically significant impairment or distress, as manifested by three (or more) of the following, occurring at any time in the same 12-month period:

1. Tolerance, as defined by either of the following:
  - a) Need for markedly increased amounts of the substance to achieve intoxication or desired effect
  - b) Markedly diminished effect with continued use of the same amount of the substance
2. Withdrawal, as manifested by either of the following:
  - d) The characteristic withdrawal syndrome for the substance (refer to Criteria A and B of the criteria sets for Withdrawal from the specific substances)
  - e) The same (or closely related) substance is taken to relieve or avoid withdrawal symptoms
3. The substance is often taken in larger amounts or over a longer period than was intended
4. There is a persistent desire or unsuccessful efforts to cut down or control substance use
5. A great deal of time is spent in activities necessary to obtain the substance (e.g., visiting multiple doctors or driving long distances), use the substance (e.g., chain-smoking), or recover from its effects
6. Important social, occupational, or recreational activities are given up or reduced because of substance use
7. The substance use is continued despite knowledge of having a persistent or recurrent physical or psychological problem that is likely to have been caused or exacerbated by the substance (e.g., current cocaine use despite recognition of cocaine-induced depression, or continued drinking despite recognition that an ulcer was made worse by alcohol consumption) (p. 197)

***DSM-IV-TR general diagnostic criteria for substance-induced psychotic disorder***

- A. Prominent hallucinations or delusions. **Note:** Do not include hallucinations if the person has insight that they are substance induced.
- B. There is evidence from the history, physical examination, or laboratory findings of either (1) or (2):
  1. The symptoms in criteria A developed during, or within a month of, Substance Intoxication or Withdrawal
  2. Medication use is etiologically related to the disturbance

- C. The disturbance is not better accounted for by a Psychotic Disorder that is not substance induced. Evidence that the symptoms are better accounted for by a Psychotic Disorder that is not substance induced might include the following: the symptoms precede the onset of the substance use (or medication use); the symptoms persist a substantial period of time (e.g., about a month) after the cessation of acute withdrawal or severe intoxication, or are substantially in excess of what would be expected given the type or amount of the substance used or the duration of use; or there is other evidence that suggests the existence of an independent non-substance induced Psychotic Disorder (e.g., a history of recurrent non-substance-related episodes).
- D. The disturbance does not occur exclusively during the course of delirium.

**Note:** The diagnosis should be made instead of a diagnosis of Substance intoxication or Substance Withdrawal only when the symptoms are in excess of those usually associated with the intoxication or withdrawal syndrome and when the symptoms are sufficient severe to warrant independent clinical attention. (p. 342)

### Personality disorders

All personality disorders are coded on Axis II of the DSM-IV-TR.

#### *DSM-IV-TR general diagnostic criteria for a personality disorder*

- A. An enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture. This pattern is manifested in two (or more) of the following areas:
  1. Cognition (i.e., ways of perceiving and interpreting self, other people, and events)
  2. Affectivity (i.e., the range, intensity, lability, and appropriateness of emotional response)
  3. Interpersonal functioning
  4. Impulse control
- B. The enduring pattern is inflexible and pervasive across a broad range of personal and social situations.
- C. The enduring pattern leads to clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- D. The pattern is stable and of long duration and its onset can be traced back at least to adolescents or early adulthood.
- E. The enduring pattern is not better accounted for as a manifestation or consequence of another mental disorder.

- F. The enduring pattern is not due to the direct physiological effect of a substance (e.g., a drug of abuse, a medication) or a general medical condition (e.g., head trauma). (p. 689)

### Attention deficit/hyperactivity disorder

#### *DSM-IV-TR diagnostic criteria for attention deficit/hyperactivity disorder*

A. Either (1) or (2):

1. Six (or more) of the following symptoms of **inattention** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

*Inattention*

- a) Often fails to give close attention to details or makes careless mistakes in school work, work or other activities
  - b) Often has difficulty sustaining attention in tasks or play activities
  - c) Often does not seem to listen when spoken to directly
  - d) Often does not follow through on instructions and fails to finish school work, chores, or duties in the workplace (not due to oppositional behaviour or failure to understand instructions)
  - e) Often has difficulty organising tasks and activities
  - f) Often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as school work or homework)
  - g) Often loses things necessary for tasks or activities (e.g. toys, school assignments, pencils, books, or toys)
  - h) Is often easily distracted by extraneous stimuli
  - i) Is often forgetful in daily activities
2. Six (or more) of the following symptoms of **hyperactivity-impulsivity** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

*Hyperactivity*

- a) Often fidgets with hands or feet or squirms in seat
- b) Often leaves seat in classroom or in other situations in which remaining seated is expected
- c) Often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
- d) Often has difficulty playing or engaging in leisure activities quietly
- e) Is often "on the go" or often acts as if "driven by a motor"
- f) Often talks excessively

*Impulsivity*

- g) Often blurts out answers before questions have been completed
- h) Often has difficulty awaiting turn
- i) Often interrupts or intrudes on others (eg, butts into conversations or games)

- B. Some hyperactive-impulsive or inattentive symptoms that cause impairment were present before the age of 7 years.
- C. Some impairment from the symptoms is present in two or more settings (eg, at school [or work] and at home).
- D. There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning.
- E. The symptoms do not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic disorder and are not better accounted for by another mental disorder (eg, Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder). (pp. 92-93)

**APPENDIX B**

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**Re: Copyright permission**

Dear Sir/Madam,

My name is Karola Mostafanejad and I am a Master of Science student at Curtin University of Technology in Perth Western Australia. I am completing my thesis on "Young adults' experience of living with a mental illness: A grounded theory approach".

In writing my methodology chapter I must include the criteria for the types of mental disorders in my study. The participants have schizophrenia, mood disorders, anxiety disorders, attention deficit hyperactivity disorder, drug induced psychosis, substance abuse disorder, post-traumatic stress disorder and personality disorder. I need to include a description of each of these disorders as an Appendix in my thesis. I would like to use the DSM-IV-TR diagnostic criteria and therefore, I am writing to seek permission to include these criteria as an appendix in my thesis. My estimated date of submission is December 2004.

Yours Sincerely

Karola Mostafanejad  
28<sup>th</sup> September 2004



**American Psychiatric Publishing, Inc.**  
**1000 Wilson Boulevard**  
**Suite 1825**  
**Arlington, VA 22209**  
**Tel: 703-907-7875**

November 17, 2004  
Karola Mostafanejad  
PO Box 118  
Geraldton, WA 6531  
Australia

Dear Ms. Mostafanejad:

I am responding to your November 4, 2004 request to reproduce the *Diagnostic Criteria for Schizophrenia, Mood Disorders, Anxiety Disorders, Substance Abuse Disorder and Personality Disorders* from the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision, Copyright 2000* in your thesis entitled Young Adults' Experience of Living with a Mental Illness in Rural Western Australia: A Grounded Theory Approach.

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Sincerely,  
Chad Thompson  
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## APPENDIX C

Example of letter sent to health services, GPs and other health agencies to recruit participants

Address to be placed here

Dear Sir/Madam,

I would like to thank you for providing this opportunity to me to recruit some young adults to my study. This is to inform you about my research study. I am currently enrolled in the Master of Science (Nursing) at the School of Nursing and Midwifery, Curtin University of Technology. The purpose of my study is to describe the experience of young consumers with a mental illness in the Geraldton community. I hope that the information obtained from this study will contribute to the understanding of what it is like to live with a mental illness from the consumers' point of view.

Information about their perceptions as consumers will be obtained through an interview lasting approximately 60 to 90 minutes. The interview will be tape-recorded and subsequently transcribed. Participation in this study is voluntary and participants can withdraw at any time without penalty.

During the interview, participants may decline to answer any question and they may ask me to cease the interview or turn off the tape recorder at any time. At no time will any participant be identified with the information they have given me in any reports or articles written concerning the outcomes of the study to protect their confidentiality. Data and tapes will be kept in a locked cupboard. Tapes will be erased at the end of the study and data will be destroyed five years after the completion of the study. I will be the only person involved in the study that will know the participant's identity.

I am interested in interviewing people who are attending Baptist Care and who:

- are over eighteen years of age and under about 30 years old
- do not have a mental or physical condition at the time of the interview that affects their ability to understand the researcher or to express their perceptions concerning their experience as a consumer.
- speak English as a first language so that no interpreter has to be used.

I will report my findings to all participants.

If you would like to find out more information about the study please contact me on or 99233741 or my supervisors, Dr Tina Ng-Tse, on 9266 2753, or Dianne Wynaden on 9266 2203.

Yours sincerely

Karola Mostafanejad

**APPENDIX D**

**Curtin University of Technology  
School of Nursing and Midwifery  
Department of Postgraduate Studies**

**INFORMATION SHEET**

**Thesis Title: Young adults' experience of living with a mental illness in rural Western Australia: A grounded theory approach.**

My name is Karola Mostafanejad, and I am a student in the Master of Science (Nursing) at the School of Nursing and Midwifery, Curtin University of Technology. The purpose of my study is to describe the experience of young consumers of mental health care in the Geraldton community. I hope that the information obtained during this study will contribute to the understanding of what it is like to live with a mental illness from the consumers' point of view.

I wish to invite you to participate in this study. Information about your perception as a consumer will be obtained through an interview lasting approximately 60 to 90 minutes. The interview will be tape-recorded and transcribed. When this process is completed I may need to make a further appointment with you to discuss or clarify issues.

Your participation in this study is voluntary and you can withdraw at any time without penalty. If you sign this consent form you are consenting to:

1. Be interviewed by myself at a mutually agreed place regarding your perceptions as a consumer of mental health.
2. Have the interview tape recorded.
3. Be re-interviewed to clarify any issues arising from the first interview.

During the interview, you may decline to answer any question and you may ask me to cease the interview or turn off the tape recorder at any time. At no time will you be able to be identified by the information you have given me and any reports or articles written concerning the outcomes of the study will protect your confidentiality. Code numbers will be given to each interview and I will be the only person involved in the study who knows your identity. If you wish to be informed about the findings please tell me at the time of the interview.

The information obtained during the interview (including the tape) will be stored in a locked cupboard during the study period. At the completion of the study the tapes will be erased. All transcribed interviews will be stored in the locked cupboard for five years after the completion of the study and then destroyed. Only the researcher and her supervisors will have access to the data. The final report will contain information collectively.

If you have any questions or require any further information concerning this study, please do not hesitate to contact me on 99233741. If you prefer, you may contact my supervisor Dr Dianne Wynaden on 9266 2203.

Thank you very much for taking the time to read this information sheet.

Karola Mostafanejad

## APPENDIX E

Office of Research and Development

**Human Research Ethics  
Committee**

TELEPHONE 9266 2784

FACSIMILE 9266 3793

EMAIL t.lerch@curtin.edu.au

<b>To</b>	Karola Mostafanejad, Nursing and Midwifery
<b>From</b>	Max Page, Executive Officer, Human Research Ethics Committee
<b>Subject</b>	Protocol Approval HR 241/2002
<b>Date</b>	13 December 2002
<b>Copy</b>	Dr Tina Ng-Tse and Dianne Wynaden, Nursing and Midwifery Graduate Studies Officer, Division of Health Sciences

Thank you for providing additional information for the project "A YOUNG ADULT'S PERCEPTION OF LIVING WITH A MENTAL ILLNESS IN RURAL WESTERN AUSTRALIA: A GROUNDED THEORY APPROACH".

The information you have provided has satisfactorily addressed the points raised by the Committee, and final approval is granted.

Approval of this project remains for the period of twelve months 4/12/2002 to 3/12/2003. The approval number for your project is **HR 241/2002**. *Please quote this number in any future correspondence.*

Maxwell Page  
Executive Officer  
Human Research Ethics Committee

J:\OR\HREC\REG99\HR 241/200

**APPENDIX F**

**Curtin University of Technology  
School of Nursing and Midwifery  
Department of Postgraduate Studies**

**INFORMED CONSENT FORM**

**Thesis Title: Young adults' experience of living with a mental illness in rural  
Western Australia: A grounded theory approach.**

I..... have read the information sheet accompanying this informed consent form relating to the study on the experience of what life is like as a consumer of mental health. I understand that by signing this consent form I am agreeing to be interviewed by Karola Mostafanejad, to have that interview tape-recorded and to be reinterviewed if necessary. I understand that I may cease the interview and withdraw from the study at any time with no penalty. I have been given a copy of this consent form. I understand that if I have any questions or concerns I can contact Karola on 99233741 or Dr Dianne Wynaden on 9266 2203 to discuss these.

Signed.....Participant

Signed .....Researcher

Date: .....

## APPENDIX G

**Thesis Title: Young adults' experience of living with a mental illness in rural Western Australia: A grounded theory approach**

### SEMI STRUCTURED INTERVIEW GUIDE

The semi-structured interview format will be used in this study. The researcher will meet with the participant approximately 15 minutes before the interview begins. During this time the researcher will establish rapport with the participant and explain the purpose of the study. The benefits of participating in the study for the participant will also be discussed during this time. The researcher will tell the participant that they will be informed of the outcomes of the study.

The interview will commence by inviting the participant to tell their story with the following statement: Tell me about yourself.

The future direction of the interview will be centred on the responses obtained from the participant's account. However the following prompts will be reflected in questions used in the interview to ensure that the objectives of the study are met.

Themes:

- What brought you to Geraldton?
- When did you notice that things were different?
- What happened when you had your [mental health episode]?
- How did the mental illness affect your life?
- What about your parents/spouse/sibling/child?
- What about your friends?
- Do you feel you are part of a group of people?
- Do you feel being accepted by society would be a desirable goal?
- Have you come up against stigma?
- Do you go out often?
- Have you thought about dying?
- What made you decide to change?
- What made you look for help?
- How was your stay in hospital?
- What was your experience with health professionals?
- How did the diagnosis affect you?
- How did medication affect you?
- What would help you?
- How can life improve?
- Do you have any regrets?
- What do you see for your future?

Following the interview the researcher will undertake a 'debriefing' period with the participant to ensure that they are not experiencing any distress from the interview. All participants will be given a card with the name of a counselling service that the researcher has arranged to be available to see any of the

participants who may require counselling as a result of issues that may have arisen from the interview.

The researcher will fill in the Demographic Information Sheet from information in the interviews.