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“If life were a line, mine would be a circle”: A phenomenological study of hospitalisation in the situation of first episode psychosis for young people, family members and nurses

Monica Margaret McEvoy RN, B.N, Grad.Dip.M.H.N.

Thesis submitted in fulfilment of the requirements for the award

Doctor of Philosophy

Sydney Nursing School

The University of Sydney

March 2013
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A phenomenological study of hospitalisation for young people with first episode psychosis
Glossary

Accuphase  Also known as zuclopenthixol acetate, a short acting antipsychotic delivered intramuscularly for the acute sedation of psychotic inpatients, effects peaking at 48-72 hours.

Attention Deficit Hyperactivity Disorder (ADHD)  A disorder characterised by an early onset (usually in the first five years of life), lack of persistence in activities that require cognitive involvement, and a tendency to move from one activity to another without completing any one, together with disorganised, ill-regulated, and excessive activity (National Centre for Classification in Health, 1998, p. 126). This disorder has been the centre of increasing debate in the last decade.

Average Length of Stay  The average of the length of stay for admitted patient episodes (AIHW, 2010, p.505).

Bipolar disorder  Also known as bipolar affective disorder, a disorder characterised by two or more episodes in which mood and activity levels are significantly disturbed, this disturbance consisting on some occasions of an elevation of mood and increased energy and activity (hypomania or mania)
<table>
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<th>Glossary Term</th>
<th>Definition</th>
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<tr>
<td>Brief psychotic disorder</td>
<td>Also known as <em>acute polymorphic psychotic disorder</em>, an acute psychotic disorder in which hallucinations, delusions or perceptual disturbances are obvious but markedly variable, changing from day to day or even hour to hour. These disorders often have an abrupt onset, developing rapidly with a few days, and they frequently show a rapid resolution of symptoms with no recurrence (National Centre for Classification in Health, 1998, p. 98).</td>
</tr>
<tr>
<td>Catatonic behaviour</td>
<td>Prominent psycho motor disturbance that may alternate between extremes such as hyperkinesis and stupor, or automatic obedience and negativism. Constrained attitudes and postures may be maintained for long periods (National Centre for Classification in Health, 1998, p. 96).</td>
</tr>
<tr>
<td>Cognitive Behaviour Therapy</td>
<td>A psychotherapeutic approach to the treatment of emotional, behavioural and psychiatric problems that helps the individual to identify unhelpful thoughts and behaviours, and to learn healthier skills and habits (Australian Association for</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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<td>-------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Delusional disorder</td>
<td>A disorder characterised by the development of either a single delusion or a set of related delusions that are usually persistent and sometimes lifelong (National Centre for Classification in Health, 1998, p. 98).</td>
</tr>
<tr>
<td>Depot injection</td>
<td>An injection of a substance, in this case antipsychotic medication, in a form that tends to keep it at the site of the injection so that absorption occurs over a period of time. This form of medication administration is usually used when medication compliance is problematic.</td>
</tr>
<tr>
<td>Duration of Untreated Psychosis</td>
<td>The period between the emergence of psychotic symptoms and the commencement of treatment.</td>
</tr>
<tr>
<td>Likert Scale</td>
<td>A psychometric scale commonly used in research involving questionnaires offering a response that ranges from strongly agree to strongly disagree.</td>
</tr>
<tr>
<td>Major depressive disorder with psychotic features</td>
<td>Marked symptoms of depression with suicidal thoughts and acts and somatic symptoms commonly present, but with the presence of hallucinations, delusions, psychomotor retardation, or stupor so severe that ordinary social activities are impossible (National Centre</td>
</tr>
<tr>
<td><strong>Midazolam</strong></td>
<td>A short acting drug in the benzodiazepine class used for inducing sedation.</td>
</tr>
<tr>
<td><strong>Negative symptoms</strong></td>
<td>Refers to those attributes that should be there, but are not, and result in symptoms such as lack of motivation, social isolation, and blunted affect.</td>
</tr>
<tr>
<td><strong>Neuroleptic Malignant Syndrome</strong></td>
<td>A life threatening neurological disorder most often caused by an adverse reaction to neuroleptic or antipsychotic drugs. Symptoms include high fever, sweating, high blood pressure, stupor, muscular rigidity, and autonomic dysfunction (National Institute of Neurological Disorders and Stroke, n.d.).</td>
</tr>
<tr>
<td><strong>Olanzopine</strong></td>
<td>An antipsychotic drug.</td>
</tr>
<tr>
<td><strong>Positive symptoms</strong></td>
<td>Those symptoms of psychosis that are not based in reality, such as delusions, hallucinations and thought disorder.</td>
</tr>
<tr>
<td><strong>Post Traumatic Stress Disorder</strong></td>
<td>Arises as a delayed or protracted reaction to a stressful event of an exceptionally threatening or catastrophic nature, which is likely to cause pervasive distress in almost anyone (National Centre for Classification in Health, 1998, p. 106)</td>
</tr>
<tr>
<td><strong>Psychotic disorder not</strong></td>
<td>Delusional or hallucinatory disorders that do not</td>
</tr>
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Glossary ix
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiridone</td>
<td>An antipsychotic drug.</td>
</tr>
<tr>
<td>Schizoaffective disorder</td>
<td>Episodic disorder in which both affective and schizophrenic symptoms are prominent but which do not justify a diagnosis of either schizophrenia or depressive or manic episodes (National Centre for Classification in Health, 1998, p. 99).</td>
</tr>
<tr>
<td>Schizophreniform disorder</td>
<td>A disorder diagnosed when symptoms of schizophrenia are present for a significant period of time within a one month period, but signs of disruption are not present for the full six months required for the diagnosis of schizophrenia (National Centre for Classification in Health, 1998, p. 97).</td>
</tr>
<tr>
<td>Substance-induced psychotic disorder</td>
<td>A cluster of psychotic phenomenon that occur during or following psychoactive substance use but are not explained on the basis of acute intoxication alone and do not form part of a withdrawal state (National Centre for Classification in Health, 1998, p. 94).</td>
</tr>
</tbody>
</table>
Candidate Statement

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed: ......................................................... Date: ......................
Acknowledgements

My thanks go to the many people whose involvement and support made this thesis possible. My thanks go to:

The young people and family members who participated in the study. They generously shared their experience at a time when they were navigating a whole new world.

The nurses who were brave enough to participate;

Professor Trudy Rudge and Associate Professor Maureen Boughton, my PhD supervisors who kept me on track. Thank you for your time, wisdom, patience and persistence;

The ‘Sydney Girls’ for your support and encouragement;

My family who have been unfailing in their encouragement;

My late parents, Dominic and Kathleen, who instilled in me a love of books and a desire to learn.
Abstract

This thesis is concerned with the experience of hospitalisation for young people with first episode psychosis. The study describes the experience of eight young people who had been hospitalised following their first episode of psychosis, and the witnessing of this hospitalisation by five family members and five nurses. The experience of hospitalisation is an inextricable part of understanding the symptoms and the impact of treatment regimes often discussed in psychiatric and psychological literature, yet it is rarely acknowledged or explored. The understandings gained from the descriptions given by the participants are explored in relation to nursing practice.

Using the early work of Martin Heidegger and the work of contemporary feminist phenomenologist Kelly Oliver to analyse and interpret the descriptions of hospitalisation, the study circles the phenomenon of hospitalisation from different textual locations. The experience of psychosis itself is traumatic and life changing. Young people and family members identify their concerns regarding their past and present experiences and future potentialities with regard to their Being-in-the-world and Being-with-others. They identify keeping connected with family, school and friends, the limitation of horizons resulting from being thrown into the world of mental illness, and finding safety and refuge in the hospital space as important in the context of disconnection and indeterminacy.

Analysis reveals the tensions for nurses between regulatory nursing practices and the social and ethical imperatives implicit in nursing positioned beside the young person. This study challenges nurses to move beyond the focus on the medicalised present and to provide space from which young people and family members can address
issues that matter to them, particularly as these relate to traumatic past experiences and future potentialities.
Preface

The research question for this study stems from clinical practice, both personal and changes in what is described as evidence based practice. My interest in this topic of research has developed over many years. In my work in Community Child and Adolescent Mental Health Services (CAMHS) in Australia and in inpatient services in the United Kingdom, I have met many young people and their families who have experienced their first and subsequent episodes of psychosis. In my clinical work with young people living in rural areas of [State] Australia where there are no specialised intensive early psychosis programs, I have met with young people who have been hospitalised following the onset of first episode psychosis. I have noted that following discharge, many spend time reflecting on their experience of hospitalisation and its impact on their life as well as their experience of psychosis. My discussions with them have revealed their anger about coercive treatment, their feeling that they had no control, and their separation from friends and family. I have also noted in my professional experience and in discussions with other clinicians that many of these young people experienced a period of hopelessness or deep sadness during their recovery. The experience of the parents of these young people has also influenced my interest in this area of research. They have relayed to me not only their own experience of seeking help for their child in a complex health system, but also their experience of witnessing their child’s experience of illness and hospitalisation in an unfamiliar and confronting environment.

Since the 1980s, the process of deinstitutionalisation in mental health services in Australia has had a significant impact on both the average length of stay (ALOS) in
psychiatric wards and the role of community based mental health services. In South
Australia, which had the lowest ALOS for CAMHS services in the country, this led
to even shorter periods of hospitalisation for young people experiencing mental
health problems. This has changed the purpose of admission and the role of nurses.
This thesis explores how hospitalisation is experienced by young people with first
episode psychosis and the implications this has for nursing practice.

Writing Up the Thesis

All the work that is not my own is referenced in the text and sources are listed in the
Reference list at the end of the document. Approval for the study was granted by the
relevant Research Ethics Committees of the Mental Health Service and Flinders
University, and endorsed by the University of Sydney Human Research Ethics
Committee (Appendix 1).

Interview extracts are in italics and indented from the left. All recorded material and
documents are verbatim transcripts. Long quotes from other literary sources appear
in block style text indented from the left. I have used footnotes to provide additional
information. Data has been edited to preserve anonymity. All names of participants
are pseudonyms. All references to the Mental Health Service or psychiatric inpatient
units involved have been removed and replaced with [Mental Health Service] or
[psychiatric inpatient unit]. Square brackets are used around any words that have
been added to interview transcripts to improve understanding. The Appendices
appear as the original, therefore they have not been formatted in the same way as the
rest of the thesis.

Some of this material has appeared as a conference paper where abstracts were peer
reviewed. Chapter 7 draws upon material presented in a conference paper entitled:

Ms Margaret Bowden provided professional editorial assistance, which was limited to Standards D (language and illustrations) and E (completeness and consistency) of the Australian Standards for Editing Practice (Council of Australian Societies of Editors) in line with the University of Sydney policy.
Chapter 1: Introduction

When a person is diagnosed with psychosis, it is a traumatic and life-changing experience, no matter at what age it first occurs. It has the potential to impact on all aspects of a person’s functioning, including interpersonal relationships and social functioning, cognition, employment and leisure. The World Health Organisation’s (WHO) World Health Report in 2001 indicated that schizophrenia and other forms of psychoses are a major public health problem, resulting in a high burden of disease, both for the individual affected as well as in costs to health systems (WHO, 2002).

When a person’s perceptual and cognitive functioning includes the presence of delusions, hallucinations and disorganised behaviour, resulting in marked loose associations and emotional turmoil, the person is said to be psychotic. Psychotic behaviours impair the individual’s ability to think, respond, remember, communicate, interpret reality, behave appropriately and meet the ordinary demands of life (Reed, 2008).

In an effort to classify serious mental disorders in the late 1800s, Emil Kraepelin created two new categories of mental disorder called dementia praecox and manic depressive illness. The former category was later renamed by Eugen Bleuler as schizophrenia. This dichotomy of schizophrenia and what is now known as bipolar disorder has pervaded Western psychiatry for over a century, influencing not only the clinical assessment and treatment of these disorders but also the research agenda, which was driven by medical and scientific schools of thought. Since the 1950s, there have been major developments in the understanding of mental health in general, and psychosis specifically, and the advancements in scientific research and
technologies were a key contributor to this new knowledge. The focus of research into schizophrenia and other psychotic disorders has changed over time, with the earlier emphasis on describing and treating symptoms, pharmacotherapies, and making the link between symptomatology and disease process being superseded in more recent years with a focus on identifying biological and genetic markers for the disease as well as early identification and treatment. As a result of the outcomes of some of this research, the Kraepelinian distinction between schizophrenia and bipolar disorders was called into question. Indeed, the diagnostic categorisation for psychotic disorders is now considered problematic, with a call for a new approach to this diagnosis (Cuthbert & Insel, 2010). The ongoing debate about the diagnosis of schizophrenia and the complexity of psychotic illnesses forms the substance of Chapter Three.

Most psychotic disorders emerge during adolescence or young adulthood, a time when there are significant ‘normative’ developmental tasks in process. Most often, an integral part of treatment of the first episode of psychosis is hospitalisation. This is usually in the context of extreme distress and high risk behaviours during which significant coercion is used, the extreme of which is detention under the Mental Health Act 2009 ([State] Department of Health, 2009). However, over the last fifteen years there has been a trend for treatment of mental health problems to be offered in the least restrictive environment; that is, to limit the use of hospitalisation as a treatment option as much as possible. Anecdotally, some describe the need to be very clear about the criteria for admission and the decision making processes with regard to the required length of stay. Moreover, much of the research into psychosis and hospitalisation has focussed on hospitalisation as a predictor of variations in outcomes (Burns, 2007; Catty et al., 2002), the cost of relapse for people with
A phenomenological study of hospitalisation for young people with first episode psychosis

schizophrenia (Fitzgerald et al., 2009), the symptomatology related to hospitalisation (Patel, DelBello, Keck & Strakowski, 2006), and the clinical outcome of hospitalisation (McShane, Mihalich, Walter & Rey, 2006). Young people are rarely questioned about their understanding of the experience of psychosis and its subsequent treatment and hospitalisation in their lives. Research to date in this area has been dominated by the scientific paradigm within which even studies intending to document young people’s experience of treatment have done so using quantitative scientific methodology, resulting in framing of data within the confines of current knowledge. I will expand on this literature in Chapter Three.

In the research that is described in this thesis I have set out to find out more about the concept of hospitalisation and how it is experienced by young people with first episode psychosis. There is significant stigma attached to mental illness, including psychotic disorders such as schizophrenia and bipolar disorder, in the broader community. People with serious mental illness not only have to deal with the impact of the illness and treatment on them, they are also confronted with the prejudices and stereotypes that exist in society about mental illness. This affects all aspects of their lives, including access to good health care, education, employment and housing, and also influencing the social groups with whom they affiliate.

**Purpose of the Study**

The purpose of this study is to explore the phenomenon of ‘hospitalisation’ for young people experiencing first-episode psychosis and the effects their experience of hospitalisation has on their experience of treatment. It is my contention that the more nurses are able to understand the experience of the young people with whom they work, the more they will be able to provide effective and useful support and
interventions, aiding optimal recovery from the outset of the acute experience of first episode psychosis.

Recent political and media attention on the state of the current mental health system in Australia and the United States has resulted in a focus on those clients accessing inpatient services, who are often referred to as ‘psychiatric inmates’ (ABC News, 2011; Starphoenix, 2013), harking back to the moral model of mental health in which the behaviour of someone experiencing mental illness violates the social mores of the time, thereby requiring containment and control (the range of conceptual models of mental health will be discussed further in Chapter Two).

In conducting this study, my aim is to extend understanding of the impact of hospitalisation on young people experiencing first episode psychosis. Understanding is a major concept on which the development of the therapeutic relationship is based. Nurses have a key role in inpatient services in establishing therapeutic relationships that are conducive to intensive assessment and intervention, and therefore deepening the understanding of nurses and others of the impact of hospitalisation on these young people has the potential to enhance nurses’ attitudes towards, and relationship with, their clients.

In order to gain access to the phenomenon of hospitalisation as experienced by young people following the first diagnosis of psychosis, I explore the issue from a number of textual locations. I have conducted interviews with young people aged between 15 and 20 years who have experienced their first episode of psychosis and have been hospitalised following that diagnosis. In addition to the interviews with the young people, I have also interviewed family members about their witnessing of the young person’s hospitalisation, providing added richness to the account. A similar number
of nurses working in inpatient units have been interviewed about their witnessing of the young peoples’ experience. One of nurses’ main roles in mental health is observational. In these interviews, I asked the nurses to move beyond the observation to bear witness to the experience of the young people rather than describing the processes involved in their care. This exploration of the witness of family members and nurses provides the opportunity to develop a comprehensive representation of the phenomenon of hospitalisation as experienced by young people with first episode psychosis. How the concept of witnessing contributes to the deepening understanding of this phenomenon is discussed further in Chapter Seven.

In addition to analysing these texts, the relevant policies and procedures that currently guide practice in this area and the Early Psychosis Intervention and Prevention (EPIP) discourses that are dominant within current literature were reviewed because they form part of the nurses’ world. In circling the phenomenon of hospitalisation in this manner, my aim is to undertake an analysis both across descriptions and between the different textual locations.

**Background**

Due to humanitarian and economic reasons, there was a shift away from institutional care for people with serious mental health problems, with the closure of many institutions and the provision of care in the community. The focus on providing care in the least restrictive environment has resulted in significantly shorter lengths of stay in inpatient units for young people with first episode psychosis. This points to a change in the purpose of the admission for these young people from being a time to reduce the symptoms of the psychosis through therapeutic interventions as well as providing psychoeducation for both the young person and their family, to a focus on
the reduction of positive symptoms of psychosis (symptoms not based in reality, such as delusions, hallucinations and thought disorder), and subsequent discharge to community care. This in turn has had an impact on the nature of the inpatient units, with an increase in turnover of more acutely unwell patients leading to a change in the role of nurses.

Another impact of the reduced length of stay is that these young people experiencing a serious mental illness are more visible in the community and are therefore more exposed to the stigma and prejudices associated with mental illness. This influences their experience of service provision and their recovery. Consumer groups have played a key role in working to reduce this stigma and prejudice in the community through mental health awareness campaigns as well as advocating on behalf of those experiencing mental illness.

**The Experience of Parents, Caregivers and Significant Others**

With the reduction in the length of stay that started with the de-institutionalisation movement in the 1980s, nursing staff recognised the need to increase the involvement of parents in order to reduce the risk of re-admission and to assist in follow up care (Scharer, 2002). Prior to this time when young people were hospitalised for medium or long term periods, parental visiting was commonly limited to one or two short visits per week. There was a common belief that parents were in some way responsible for their child’s mental illness and that separation was required to enable the young person to discard ineffective coping skills and to develop new ones (Harper & Cotton, 1991). This practice reflects the beliefs about the parental influence in the psychoanalytic model of mental health, which is discussed further in Chapter Two.
However, the reduced length of stay required child and adolescent mental health units to engage parents as part of the treatment team. There was even a suggestion that the treatment team works for the parents (Harper & Cotton, 1991). More recent research has found that parents need and want more information and communication about their child’s diagnosis and care, instrumental support including access to their child, and emotional support for both themselves and their child (Scharer, 2002). Some carers find themselves working in consumer advocacy groups because they are unable to work directly with the treating team. Such a consequence creates a dissonance between the goals of a reduced length of stay and parental engagement.

**Adolescent Psychiatry**

Serious mental illness is relatively rare amongst adolescents; however there are claims that, though rare, serious mental illness results in more social problems due to the lack of adequate and effective services provided for this group rather than because of the illness itself (Amminger et al., 2006). The stigma attached to the diagnostic labels such as schizophrenia and bi-polar disorder evoke fear of inevitable and irreversible breakdown (Sandamas, 2004).

As a result of improved living standards in the Western world, adolescents are seen as having good health and few specific health provision needs. The perception of the needs of adolescents with mental health problems has shifted over the last 30 years due to epidemiological studies such as the “Isle of Wight” study, which indicated that emotional upheaval was not necessarily a normal part of adolescent development (Rutter, 1985). These studies revealed that most young people negotiate adolescence without excessive turmoil. Other researchers dispute this, suggesting that the physical and psychological changes that adolescents go through do result in
behaviour that appears to be irrational and unreasonable (Hill, 1989). While “The Isle of Wight” study indicates a prevalence of up to 15% of school aged children experiencing significant mental health problems, it is suggested that this prevalence has increased markedly in recent years (Amminger et al., 2006; McGorry, 2000). The incidence of first episode psychosis is reported to be 2.2 per 10,000 in the Netherlands, 3.09 in the United Kingdom (UK), while in Australia it has been reported to be 16.7 per 10,000 for males and 8.0 per 10,000 person years for females (van Dusseldorp, Goossens & van Achterberg, 2011). It should be noted that researchers in this area have, in later years, focussed on the 16 to 30 year age group rather than the under 18 year age group, thereby making statistical comparisons difficult. In addition, such a discrepancy in incidence rates suggests that different criteria have been applied to the diagnosis of first episode psychosis in Australia.

Adolescent Mental Health Nursing

The movement towards subspecialisation in the field of child and adolescent psychiatry began to accelerate after the Second World War, with the American Academy of Child Psychiatry being established in 1953 (the academy expanded its name to the American Academy of Child and Adolescent Psychiatry in 1986). Nurses have been involved in delivering care to people suffering from mental illness for many years. However, it was only in the second half of the 20th century that the subspecialty of child and adolescent psychiatric/mental health nursing emerged. The Association of Child and Adolescent Psychiatric Nurses was founded in 1971, and specialist training in child and adolescent mental health nursing began in the UK in 1975. Nurses have been working in the area of child and adolescent mental health for over 30 years now, yet often there is a lack of clarity about their contribution to the multi-disciplinary team.
The establishment of specialist adolescent inpatient psychiatric units in [State] occurred over 30 years ago. The community Child and Adolescent Mental Health Service (CAMHS) clinics grew out of the Child Guidance movement, which was staffed primarily by social workers and psychologists (although the exact staffing did vary considerably). In the 1980s, departments of child psychiatry took over this role and a more medical model came to dominate. While social workers still work in child and adolescent mental health services across the country, the service is now seen to be a ‘health’ service to which social services contribute. There was a lack of reference to the development of community nursing positions and therefore an absence of detailed rationale for their inclusion in CAMHS teams (Baldwin, 2002).

Prior to this time, nurses’ roles were considered to be in inpatient settings where their practice was dominated by the medical model. Following the process of deinstitutionalisation, the need for nurses in community mental health teams to administer and monitor medication became evident. In CAMHS services, where medication is prescribed at a much lower rate than in adult services, nurses’ roles focussed on assessment and therapeutic interventions.

In nursing literature, specific knowledge is claimed as essential to mental health nursing, including the fostering of hope, the therapeutic relationship and milieu, advocacy and healing (Pond, 1988; Niemela, Poster & Moreau, 1992; Byrne et al., 1994). However, other research indicates that other specialist nurses share the characteristics and knowledge claimed to be specific to mental health nursing (Benner, 1984). Nurses such as Geanellos (1995) proposed that it is possible that mental health nurses use the foundation of generic nursing knowledge differently, however there is no research to support this to date.
There is very little research explicating the practice of mental health nurses in adolescent mental health settings. Geanellos explored adolescent mental health nursing practice knowledge, identifying ways in which mental health nurses “...cocreate transformative relationships with clients” (Geanellos, 2002a). She claims that the purpose of the nurse-client relationship is to work towards fostering a functional self, and that reintegration and transformation are the focus of mental health nursing practice. While Geanellos includes the voices of young people in her research, she does so in order to identify what mental health nurses do and how they do it rather than the meaning the young people give to their experience of the nurse-client relationship. Her work was aimed at explicating the ill-defined role of the mental health nurse in adolescent mental health inpatient settings in order to challenge the use of theory borrowed from the disciplines of psychiatry, psychology and social work.

Other researchers have also sought to analyse the nature of nursing interventions in the recovery from psychosis (McCann & Maker, 2001; Freeman, 2002; Forchuk, Jewell, Tweedell & Steinnagel, 2003). However, the phenomenon of hospitalisation as experienced by young people with first episode psychosis has been ignored by researchers, including nursing researchers.

**Mental Health Nursing and First Episode Psychosis**

Psychosis usually first occurs in adolescence, a time when young people are developing their social networks outside of their family and exploring their role in the world (Mackrell & Lavender, 2004). Considerable research has been undertaken in the areas of early identification and treatment of psychosis, and mental health guidelines have been developed in the United States (US), the UK and the
Netherlands to guide practice in the treatment of diverse mental health problems. However, very little of the information provided by the research and guidelines speaks in any depth about the treatment of first episode psychosis and specifically about the contribution of mental health nursing to the care and treatment of young people with first episode psychosis (van Dusseldorp, Goossens & van Achterberg, 2011). As nurses make up the majority of the mental health workforce in most psychiatric inpatient units, it is important to explicate the nursing interventions that are effective in the treatment of first episode psychosis. The research in this area will be discussed in detail in Chapter Three. Equally as important is understanding the effects of the different aspects of treatment on the young person receiving the treatment, and to do so, we must listen to the young people themselves and the people who care about them and support them through this treatment.

**Structure of the Thesis**

This thesis is presented in nine chapters. Chapter One introduces the study with a broad background about first episode psychosis and mental health nursing, and the general purpose and aims of the research. Chapter Two gives an historical analysis of the theories of mental illness that have influenced the nature of mental health care over the centuries. The models of mental health that have been developed in the 20th century are examined in the light of current child and adolescent mental health practices. The challenge to the dominance of the scientific or medical model is discussed along with Heidegger’s philosophical analysis of science.

Chapter Three provides a selective review of the vast literature in first episode psychosis and an analysis of the contemporary debates regarding early identification and intervention in this field. The role of nurses in the treatment of first episode
psychosis is also examined. Chapter Four details the phenomenological research approach and its application to nursing research, and the methods applied in this study.

Chapters Five, Six, Seven and Eight discuss the findings of the research which was guided by the work of Martin Heidegger (1962) and contemporary phenomenologist Kelly Oliver (1998, 2001, 2004). Chapter Five examines the impact that being thrown into the world of mental illness has on young people’s relationship with the world. Chapter Six discusses the role of labelling and stigmatisation on their relationships with others and their hopes for the future. Chapter Seven contrasts the concept of care in mental health nursing with Heidegger’s notion of care, and explores Oliver’s concept of witnessing as a way of understanding young people’s apprehensions of illness and hospitalisation. Chapter Eight discusses the hospital space as a place of temporal refuge and safety, in both physical and relational terms. Chapter Nine summarises the study findings and their implications for nursing practice. It also looks at the limitations of the study and provides recommendations for future research.
Chapter 2: The History and Conceptual Understandings of Psychosis

Introduction
The current understanding of mental illness has been shaped over many centuries and remnants of conceptual models that are no longer considered credible remain embedded in current discourses and practices regarding first episode psychosis. In this chapter, I explore the history of madness over the centuries and the conceptual models that have guided practice in the care of those with mental illness in the 20th century. This provides the historical and sociological context underpinning the biological and psychiatric discourses that dominate contemporary debates and understanding of psychosis but are rarely named. A discussion of Heidegger’s philosophical analysis of science and his concept of reflection and its application in understanding the experience of hospitalisation for young people with first episode psychosis follows. With this context, this study explores the phenomenon of ‘hospitalisation’, moving beyond the scientific paradigm and traditional technological statements, using a phenomenological method of enquiry to be open to and inclusive of the entirety of the experience itself.

History of Mental Illness and Treatment
In sketching the history of mental illness, this section relies on the work of Roy Porter, a medical historian who has written prolifically about the historical understandings of madness. He traced and mapped out the centuries of understandings of what mental illness is, and how it should be treated, which have influenced collective attitudes towards people who suffer from mental illness. Porter (1987) links Western understandings of madness back to the ancient Greek poets and
playwrights who portrayed their heroes as people at the mercy of forces beyond their control (gods, demons, fate). During the 5th and 4th centuries BC, the development of philosophical thought subjected nature, society and consciousness to reason. Rationality became the most important faculty in man [sic]. While Greek philosophers acknowledged the reality of what was not rational, reason was seen as the construct with which to combat irrationality.

…the dichotomy between the rational and the irrational, and the rightful sovereignty of the rational, became fundamental to both their moral and their scientific vocabulary, and through them, to ours. (Porter, 1987, p. 11)

This dichotomy continues to have a strong presence in current conceptualisations of mental illness, with rationality and safety being the key criteria on which decisions are made regarding the use of coercive treatment orders using the Mental Health Act 2009 ([State] Department of Health, 2009).

The Greeks developed medical theory as a way to cope with madness. In claiming that epilepsy, which had previously been seen as a sacred disease (one inflicted by the gods), was actually a physical illness, this left the door open for all madness to be explained through medical theory. Two rival explanations of madness evolved – madness seen as badness or as disease – in both of which the insane person is seen as less than fully human. Medieval Christendom absorbed both of the Greek alternative explanations of madness – madness as moral trauma and madness as disease – but also saw the treatment of madness as a mark of the war waged between God and Satan for the possession of the soul. Through the Middle Ages, insane people rarely had any special provisions made for them. While a small number of homes were set up for the insane, most lunatics were the responsibility of the family and village
community. Porter claims that the retention of the insane in the community reflected the preservation of some residual sense of common humanity, in line with the Christian belief that all beings are created in God’s image, whether insane or not (Porter, 1987). It is not clear what level of care and protection was afforded those with mental illness as the traditional state or government at this time undertook limited welfare functions. Viewing behaviour through the dichotomy of mad and bad persists in the mental health and forensic systems today, with the mental illness defence legitimised as grounds for behaviour not sanctioned by society. The over-representation of people with mental illness in Australian prisons speaks to the lack of clarity in this dichotomy, raising questions about its usefulness as an explanation of mental illness.

Segregation of those with mental illness started in the 17th century when movements of exclusion were activated, particularly for those who were seen to be displaying delinquent and dangerous traits. During the Enlightenment, the Greek distinction between ‘reason’ and ‘unreason’ became even more important. Those who demonstrated concern towards people with mental illness imposed social norms that distanced them, seeing them as strange and different from themselves. The main reason for confinement was dangerousness and the maintenance of social order rather than the betterment of mental health. Institutions were provided for locking away the worst offenders, both to protect society and in an attempt to reform the insane. Through the 18th and 19th centuries, a proliferation of institutions including schools, prisons and madhouses were established to “…deal with the menace of unreason” (Porter, 1987, p. 16).

The focus on ‘curing’ the insane started in the mid-18th century, with new
management techniques that strengthened the reasoning for segregation. While the incarceration of the insane remained the initiative of magistrates, philanthropists and families rather than doctors, the rise of the insane asylum resulted in the development of *psychological* medicine. The medical interest in madness, the mechanical models of body and mind, and what was seen as the growing role of the central nervous system in producing behavioural and perceptual disturbances, was embedded in the expectation that the cause of insanity would be found in organic, neurological or biochemical disorders. This expectation persists today, with the vast majority of funding for research in mental health and psychiatry going to empirical scientific studies.

The specialist branch of medicine termed ‘psychiatry’ is anchored in the asylum movement of the 18th century. Physical, mechanical and pharmacological treatments were common, grounded in the concept that treating the body would have an impact on the mind. Those experiencing mania were sedated; melancholics were stimulated; constitutions were purged of poisons; electric shock treatments were common; manacles, straight-jackets and manual labour treated the mentally ill body. The ultimate aim was to calm the mind, re-inviting a reconnection to reason through such bodily treatments.

It was at this time, based on the work of philosopher John Locke and his theory of human understanding that reformers of psychiatry stressed that the madman was not completely devoid of reasoning power, but that the disturbed connections of feelings and ideas resulted in false conclusions about reality and proper behaviour. Virtually simultaneous revolutions of the treatment of the mentally ill occurred in Italy, France and England, which led to the expansion of opportunities for re-programming and to
a re-enforcement of the need for asylums. If there was a cure for madness, then it was society’s duty to place the mad in institutions where they could access this psychiatric cure. These alternative asylums had programs based on spiritual and moral beliefs in which individual freedom was respected. They advocated for a more humane and progressive attitude towards those with mental illness, with the institution providing a safe retreat where harmony and tranquillity were evident. However, with the sudden growth in the number of asylums required to accommodate the increased number of people being referred for care, the high standards of the original asylums involved in the reform were not maintained. The size or homogeneity of the communities was not regulated, with the acutely unwell being housed in large numbers with the chronically ill, senile or alcoholic patients in large, unruly institutions. This has left us with terms such as ‘bedlam’ or ‘madhouses’ used as metaphors for places or spaces of chaos and confusion. The fact that the majority of patients in the asylums did not return to normalcy led to the belief that insanity was indeed incurable, and, at worst, that asylums themselves were machines for the ‘manufacture of madness’ (Porter, 1987, p. 20). This also reinforced the view of medical theories that insanity is essentially a physical disease inherent in the individual.

A ‘degenerationist’ school of psychiatry, in which insanity was seen as a throw back, developed in the social context in which artistic and literary geniuses, including Impressionists, Cubists and authors who challenged the current norms, were seen to be suffering from moral, mental or visual disorders, and denounced as decadents. The fear that the dangerous masses would change civilisation emerged at the same time as Darwinism stated that, as in nature, only fit societies would survive. Porter states that psychiatry had become more pessimistic and it was in this context that
German psychiatrist Emil Kraepelin developed the concept of *dementia praecox*, which would later be named schizophrenia. Kraepelin’s description of the schizophrenic as someone who had renounced his humanity, abandoned his desire to be part of human society, is seen by Porter as a further attempt to set this group of people aside from the general populace and to portray them as somehow morally corrupt. Eugen Bleuler, who renamed the concept *schizophrenia* in the early 20th century, further explicated the symptomatology that demonstrated these people could not be treated as equals: that their communication was nonsense and held no real meaning or reasoning.

The pessimism Porter refers to has not shifted over time. A recent study found that, in terms of recovery or cure in serious mental illness, psychiatrists are the most pessimistic of the health professionals who provide care for the mentally ill in contemporary society (Jorm, Korten, Jacomb, Rodgers & Pollitt, 1997). This reflects the degree to which the stigma of mental illness influences not only the broader community, but also the health professionals providing care for those with mental illness. The extent to which this is a factor in adolescent inpatient units is an issue that does not register in the literature.

It was not until the turn of the 20th century that the practice of talking therapies became commonly used. Psychiatrists such as Freud developed therapeutic interventions based on the relationship between the psychiatrist and the patient. Freud acknowledged that this new therapy could only be useful to mildly disturbed people because it required the patient to have a good sense of reality and a capacity for emotional interaction. Those with serious mental illness such as psychosis remained untreatable and were categorised as incurable.
As the discipline of psychiatry has grown, it has pathologised behaviour which Porter claims was once “…left to the bench or the pulpit” (Porter, 1987, p. 23). Excessive alcohol intake became alcoholism, certain homosexual behaviour became homosexual neurosis, and more recently, highly active children have Attention Deficit Hyperactivity Disorder and those who have not adequately internalised accepted behavioural norms are diagnosed with Conduct Disorder. The stories of the insane that are recounted by Porter point out that psychiatry has a tendency to be “…grandiose but circular: it saw madness everywhere” (Porter, 1987, p. 23). The isolating of people experiencing mental illness and secluding them in institutions reinforces the strangeness of those institutionalised, removing them from their wider social context and replacing that with the clinical context.

Significant developments over the centuries in the history of mental illness and psychiatry have contributed to seeing the mentally ill person as a symptom, a diagnosis and a process for treatment. Society has defined itself over the centuries as rational and normal, thereby stigmatising and excluding those that do not fit within this conceptual analysis, rendering them strange or somehow a non-person.

One of the major reforms in psychiatry in the 20th century has been the community mental health movement, which commenced in the middle of the century. Mental health legislation in many parts of the world in the last 50 years has supported the concept of care in the least restrictive environment and rehabilitation driven services for the mentally ill in the community. More recently in Australia there has been a focus on recovery rather than rehabilitation, emphasising and supporting each individual’s potential for recovery and social inclusion. The movement towards deinstitutionalisation in the 20th century was accompanied by concepts such as access
and equity, the early identification and treatment of mental illness, and the acknowledgement of a spectrum of theoretical models that influence professional practice.

Progress towards deinstitutionalisation and community integration is dependent, in the main, on three issues. The first is the level of stigma attached to those with mental health problems. This remains a major influencing factor in the treatment received by those suffering from mental illness (Hinshaw, 2005). The growth in the consumer advocacy movement in mental health has aimed to reduce stigma by challenging ill-informed beliefs and attitudes towards mental illness. The consumer movement, comprising mental health service users and carers, has also actively sought to influence the development of policies and procedures that guide assessment and treatment of those with mental health problems, including addressing the institutional nature of the mental health system.

Secondly, the process of deinstitutionalisation requires appropriate funding. There is no evidence that community based services, including clinical services and supported accommodation, cost less than institution based services or that they have been funded at the level required for the support of a person with a diagnosis of mental illness or their families.

Thirdly, deinstitutionalisation involves a major shift in thinking – from the concept that the institution of psychiatry has, as its primary object, the control of behaviour and thoughts that depart from the norm, to “… a renewed therapeutic intention in psychiatry which must take responsibility … for restoring the rights of citizenship to persons who are in a state of suffering” (Colucci, Norcio & Sindici 2000, p.9).

Basaglia, a Venetian psychiatrist who introduced major reform in the mental health
system in Italy from the 1960s, claimed that the practices of the asylum institution concealed the suffering and needs of the ill person:

We produce its symptomatology – that is the way in which the illness expresses itself – based on the way we intend to deal with it, because the illness always constructs and expresses itself with respect to (or in the image of) the means which are adopted in order to handle it. (Basaglia 1975, cited in Colucci et al., 2000, p. 4).

In institutions, it is the needs of the institutional organisation that are recognised, while the needs of the ill person become invisible. Basaglia argues that psychiatry must work with the community as a whole to address the needs of the individual person in the context of the needs of all. These needs are fundamental:

… the right to health and well-being in one’s relationships and living spaces, the right to a secure job that does not wear one down physically or morally, … the right to cultural enrichment and leisure time, … and the right to participate in the fight against the various forms of exclusion. (Colucci et al., 2000, pp. 5-6)

For deinstitutionalisation to be successful, the treatment of those with mental health problems requires a move beyond the medical model to encompass other significant aspects of people’s lives, including employment, education, housing and leisure.

The history of mental illness and its treatment reveals a range of theoretical models that continue to influence professional practice in mental health care and which colour the way in which a person with psychosis is seen by health professionals. These conceptual models provide the basis from which health professionals work,
whether or not their origin or limitations are understood.

**Models Developed in the 20th Century**

In addition to the historical conceptual models of mental illness, a range of conceptualisations emerged in the 20th century that have explored the causative nature of mental illness. These have been summarised by Siegler and Osmond (1974). Throughout the 20th century, these models have influenced the way in which psychosis is defined and understood, and they have shaped, and continue to shape clinical practice, even though many of them are no longer considered convincing. The divergence that exists between these models underlies the debate that began in the late 20th century regarding the nature and treatment of psychotic illness, a debate to be further discussed in Chapter Three.

Siegler and Osmond (1974) identified eight models of mental illness: medical, moral, psychoanalytic, family interaction, conspiratorial, social, psychedelic and impaired models. The medical model is one that has gained importance in the 20th century, in the main to the exclusion of other models. This is evidenced by the push to seek biologically based answers to questions raised by the experience of mental illness and the high percentage of traditional, scientifically based research into psychotic illness. In the biomedical model, the patient is considered to be sick. While the basic clinical sciences (pathology, physiology and anatomy) have failed to reveal the precise cause of psychosis, the cause of the illness is assumed to be a ‘natural’ one; that is, it is the result of the malfunctioning of the body. In the medical model, once the diagnosis is made using systematic clinical observation, the treatment and prognosis can be determined by the doctor. In the medical model, roles of staff and patient are clearly defined: “Doctors treat the ill, nurses care for them, other staff
rehabilitate them”, with the patient having a “right to the sick role” as long as they try to get well (Siegler & Osmond, 1974, p. 17).

In the treatment of psychosis, there is strong support for the treatment of choice being neuroleptic medication (Thomas, 2002), but there continues to be debate about the effect of neuroleptics on the course of the illness. Research into the prognosis of people experiencing psychosis has predominantly been undertaken with people experiencing chronic schizophrenia and long term institutionalisation. Ciompi (1980) found that the main field of impairment that was an indicator of intermediate or poor outcomes in schizophrenia was not the symptoms of the illness but social functioning. Given that the people participating in the research had been institutionalised for decades, this is hardly surprising and may have little to do with the progress of the illness. This raises the question as to whether the poor outcome is actually an artefact of institutionalisation (Thomas, 2002).

The shift towards community care of people experiencing psychosis and reducing the length of stay in hospital may have an impact on the prognosis, but the causal nature of impact is as yet unknown. People experiencing psychotic disorders exhibit varying degrees of insight into their illness and adverse effects of neuroleptic medication have a significant impact on their daily lives, hence compliance with treatment remains problematic. In the medical model, the decision of the client to discontinue treatment is seen as a challenge both to the professional’s expertise and to the client’s “right to the sick role” because they are seen as not trying to get well.

*The moral model* incorporates both religious and behavioural aspects. It is the behaviour of someone experiencing mental illness that violates the social mores of the time. The behaviour becomes the focus rather than the illness, resulting in
therapy that aims to have the individual take responsibility for his or her behaviour so that it becomes socially acceptable. While society has a responsibility to provide opportunities for rehabilitation, it also has the right to defend itself against aberrant behaviour. The moral model was at its strongest in the Middle Ages and while it has little support in literature today, the remnants of it can be seen in some substance misuse programmes based on the twelve step process. Another example of the influence of this model is the recent debate here in Australia and the US about security of our psychiatric institutions, in which those experiencing mental illness have been branded ‘psychiatric inmates’ in an apparent reference to a breach of society’s social mores (ABC News, 2011; Starphoenix, 2013). Although this model is not currently accepted in its pure form, the recent emphasis on the individual’s capacity for ‘self-management’, requiring the individual to take responsibility for managing their treatment to ensure that their behaviour remains within socially acceptable limits, is another example of the influence of this model in current practice.

The impaired model considers the person to be permanently disabled by the illness, and the main aim of therapy is rehabilitation and protection from exploitation or persecution. The limitations of the disability are accepted and the person is encouraged to ‘be as normal as possible’. The limitations are spoken of openly so as not to give unrealistic hope. Elements of this model are reflected in services provided for those with chronic mental illness, particularly those who have been institutionalised for long periods of time, where employment, education and leisure options are non-existent. This model has been challenged by Italy’s Trieste Mental Health Services, where employment and accommodation services are an integral part of their service provision in collaboration with local businesses (Trieste Mental
Health Department, n.d.).

*The psychoanalytic model* seeks to provide an explanation of the causes of psychosis through an exploration of emotional distress. The basis of the psychotic experience is seen to lie in traumatic experiences, particularly those in early childhood. Psychoanalytic techniques such as dream analysis and free association are used along with comprehensive history taking to understand the origin of the illness. The relationship between the patient and the therapist is the pivotal tool used in treatment to assist the patient to gain insight into his or her illness. Treatment can occur anywhere that is away from the family that has made them sick. The intense focus is on the individual in an acontextual framework, and it is the individual’s responsibility to gain ‘insight’ into his or her problem.

It was within the context of the psychoanalytic model that theories such as ‘schizophrenogenic mother’ arose. This term was first used by psychiatrist Fromm-Reichmann in 1948 to describe schizophrenia as a reaction to a morbid family environment in which the mother, by her behaviour, isolates the child and induces psychosis. In exploring this concept, Lidz (1973) described an outwardly harmonious family, termed *skewed*, which is characterised by a mother who is exceedingly intrusive in her child’s life and overprotective, feeling that the child cannot exist without her supervision. Arieti argues that schizophrenia can be understood as an injury to the inner self, inflicted by psychologically invasive schizophrenogenic parents (Arieti, 1955). The tendency to look to the mother/child relationship to explain a psychotic illness is not uncommon even today. It is embedded in subtle ways (and some not so subtle ways) in some current assessment and treatment practices, as seen in the way carers feel they are treated when their loved one is...
admitted to hospital. Practices such as limiting the young person’s contact with their parents while they are in hospital reflect a censorious attitude towards parents, implicitly placing blame on them for their child’s illness.

_The family interaction model_ purports that while the individual may be the person diagnosed with an illness, they are actually bearing the illness of the family. It is only through therapy with the whole family that changes within the family system can occur and the ‘index patient’ can be released of the burden of carrying the family ‘illness’. While this model is not central to the delivery of services to individuals with serious mental illness, it is very influential in the services provided to children experiencing emotional or behavioural problems, and their families. There is an expectation that the family, particularly the parents, will participate in therapy. Terms such as ‘the identified client’ imply that the whole family is the client.

_The conspiratorial model_ has its roots in the anti-psychiatry movement. Szasz (1970) claimed that mental illness did not exist and that an intolerance of deviance in society has led to the classification of those who step outside society’s norms as either mad or bad. The concept of “treatment” is seen as a kind of brain washing to induce conformity. Foucault (1972) identified three major factors in the “discursive production of madness” – disciplines, commentary and author. The disciplines of psychology, psychoanalysis and psychiatry are the ‘experts’ in mental illness in our culture. Specific authors, who hold esteemed places in their disciplines, produce texts that provide commentary on, and produce ‘madness’. The ‘dominant knowledges’ of psychiatric institutions are translated into an ‘objective reality’ which, in the treatment of first episode psychosis, includes limited visiting hours, limited access to information, the labelling of significant others, and a de-valuing of other relevant
The social model of mental illness equates a sick individual with a sick society. This model is often used by epidemiologists, for example those who are looking at the correlates between behaviour problems in children under five years of age and criminal behaviour in adults. This model also often underpins health promotion and prevention strategies such as those identified in the Australian National Mental Health Plans (Australian Health Ministers, 2003).

The psychedelic model sees madness as a response to an intolerable family situation and that the mad see things more clearly than the sane. Led primarily by R. D. Laing, this model views the behaviour of those experiencing psychosis as an escape from a difficult family situation, a sane response in an insane situation, and therapy involves a guided journey through the madness to enlightenment. Others have argued that Siegler and Osmond’s analysis of Laing’s work is simplistic, not commenting on the emphasis that Laing places on the meaningfulness or importance of the context of the behaviour of a person experiencing psychosis (Walton, 1995). The behaviour of someone diagnosed with schizophrenia is not meaningless but can be understood in the context of their experience in their interpersonal relationships. The meaning contained within a person’s behaviour and hallucinations is not often elicited or seen as significant or important by mental health professionals when the person presents for treatment of psychosis.

It should be noted that Siegler and Osmond overtly privilege the medical model over all other models, stating that it has:

… a significant advantage in conditions such as schizophrenia, in that it alone offers a dignified status for the person who cannot occupy his [sic] usual social
role for reasons completely beyond his control. (Seigler & Osmond, 1974, p. 20)

The diversity of the explanatory models for psychosis in the 20th century in part reflects the divergent views of the causal factors involved in psychosis and the subsequent treatment options. The contemporary debates and understandings of psychosis are discussed further in the next chapter.

*The stress-vulnerability* or stress-diathesis view is a model that has been developed since Siegler and Osmond completed their synthesis. This model acknowledges the multiple influencing factors in those who are vulnerable to the experience of psychosis, including genetic, pharmacological, environmental and social factors (e.g., homelessness and unemployment). It also acknowledges that the medical model does not provide the framework to understand the complexity of the context in which psychosis emerges, and the impact of assessment and treatment on progression of the illness (Ingram & Luxton, 2005). It also embraces theories of psychosis that explore sociological factors such as the Social Defeat Theory of schizophrenia, which proposes that chronic and long term experience of social defeat leads to a sensitisation of the mesolimbic dopamine system, thereby increasing the risk for schizophrenia (Selton & Cantor-Graae, 2005). Perceived discrimination has also been found to be a risk factor for the development of psychotic symptoms (Janssen, et.al. 2003), further supporting the stress-vulnerability model as a way of conceptualising mental illness.

**The Challenge to the Dominance of Scientific Method**

The medical or scientific model has been the most dominant in its explanation of mental illness in the 19th and 20th centuries. There is no denial that such a model has
produced significant developments in the understanding of the biological processes that underpin symptomatology. The pursuit of scientific endeavour is highly respected and rewarded in our culture. There has been prolific research in the areas of psychosis, early intervention and treatment options, the majority of which has been undertaken using scientific methodology. New phenomenon manifesting itself within the scientific arena is refined to fit the standard understanding of the theory, and when that proves difficult, as in the current debate on the reliance on the Kraepelian dichotomy to understand psychotic illness, the focus of research shifts (in this case) to identifying biological and genetic markers for the disease (this will be discussed in more detail in Chapter Four). However, it is my case that the structure and processes of scientific methodology limit the descriptions of the experience of psychosis and treatment to that which has already been objectified.

Therefore, using a process of reflection on that which is ‘worthy of questioning’ enables a researcher to move beyond the object that is explored using scientific methodology to the essence of the phenomenon that has been identified, rather than a search for causes. In this next section, I am turning to the work of Heidegger to problematise and contest the dominance of science in the exploration of phenomenon. I explore Heidegger’s philosophical analysis of science and his concept of reflection, and look at its potential for understanding the entirety of the experience of hospitalisation for young people with first episode psychosis.

**Heidegger’s philosophical analysis of science and reflection**

In exploring the reason behind the dominance of science in modern thinking and knowledge development, Heidegger looks back to Ancient Greek and Roman philosophical interpretations of fundamental concepts. The Ancient Greeks believed
that the essence of science is not just *what* science is, but the way in which it pursues its course over time. A purely cultural view of science does not gauge the scope of its essence. Rather, Heidegger suggests that the essence of science can be expressed in the axiom, “Science is the theory of the real” (Heidegger, 1977, p. 158).

The current understanding of science is very different from that of the Middle Ages or Ancient times. The current essence of science is grounded in Greek philosophy, particularly in the essence of knowing. Our present day world is completely dominated by the desire to know more about modern science. Heidegger argues that Greek thought and poetry are still present in today’s understanding of science, not just as a re-working of ancient ideas or an historical curiosity that could explain current trends as we see them. The essence of the philosophy of knowing is hidden in the rule of modern technology, which although totally foreign to the ancient world, has its essence at its core.

In exploring the basic principle, “Science is the theory of the real”, Heidegger first looks to the word *real*, meaning ‘to work’ or ‘to do’. ‘To do’ is either something becoming manifest and presencing itself, or the bringing forth is accomplished by human beings. Heidegger uses the term presencing to describe, “… the enduring of that which, having arrived at unconcealment, remains there” (Heidegger, 1977, p. 161). Aristotle’s fundamental word for presencing was *energeia* or ‘enduring-in-work’. This is a very different concept from the more modern meaning of the word *energeia* in the sense of ‘energy’ being talent and capacity for work. Heidegger argues that Aristotle’s meaning of the word *energeia* has been suppressed in favour of the Roman translation, *actus*, with the term ‘think’ (*ergon*) being translated as *operatio*, both of which have a totally different realm of meaning. So, the
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phenomenon that becomes ‘real’ now does so as a result of an action. A result is that which follows a consequence or an out-come. The real is now that which has followed the consequence and the consequence is brought about by the cause (Heidegger, 1977).

This constitutes a change in the understanding of the real. The consequence shows itself as a result of the action, as performed and executed by human beings. What follows from an action is seen as factual. The real now shows itself as object, limiting the understanding of real to object rather than that which endures through work.

The term ‘theory’ stems from the Greek verb *therorein*, a combination of two root words: *thea* and *horao*. *Thea* is the outward look, the outward appearance in which something shows itself. *Horao* means to look attentively and closely. Therefore, theory is “…to look attentively on the outward appearance from which what presences becomes visible and, through such sight – seeing – to linger with it” (Heidegger, 1977, p. 163). In Greek philosophy, theory devoting itself to focussing on that which emerges and endures is seen as the purist form of thinking. In contrast to this is the way of life dedicated to action and productivity. The Roman translation of *therorein* is *contemplari* – to partition something in to a separate sector and enclose it within for observation.

So the meaning of theory has moved from looking attentively at the aspect of that which emerges and endures, to observing and considering that which can be partitioned off. Modern science as theory strives after a reckoning of the real to bring it to what Heidegger calls ‘objectness’; ordering it in to a surveyable series of related causes, immobilising the real in objectness.
Characteristic of this objectness is that it maps out in advance the possibilities for questions. Every new phenomenon that arises in an area of science is seen within the context of what is already understood. For example, reactions to treatment of psychosis are viewed within the constructs of the impact on symptomatology, known diagnostic categories such as Post Traumatic Stress Disorder (PTSD), and the impact on functioning as assessed using accepted tools. The method of defining the real in modern science is seen as the dominant methodology, gaining strength in the 19th and 20th centuries. The procedure attached to the scientific methodology is one of compartmentalising. Any investigation must comply with the structure and process belonging to that area of science. Heidegger sees specialisation in science as an inevitable and positive consequence, and it is the juncture where these specialisations meet that provides the opportunity for the formulation of new questions and new understandings.

Heidegger explores what he calls the inconspicuous state that is hidden in the essence of science. Scientific theory identifies the real and compartmentalises it in order to observe and classify it. Nature is always manifesting itself in enduring ways, and scientific objectification is directed towards nature and its manifestations. Science aims to know nature – through making a series of things, with evolution of knowledge, each bit adding to the knowledge of the last, leading to the accretion of knowledge. Scientific theory cannot step ahead of nature – nature is already manifesting itself, “… and in this sense theory never makes its way around nature” (Heidegger, 1977, p. 173). Take the example of psychiatry, which observes the human being and mind in its sick (and therefore healthy) manifestations. It represents these in terms of signs and symptoms of the mind, body and spirit of the human being. What psychiatry is observing is human existence displaying itself. Humans
display various ways of being, and biology, psychology and spirituality are some of the innate ways of human beings in the world. This remains the part of nature that psychiatry cannot objectify or outstrip.

The reason science cannot outstrip nature is embedded in the principle that the object, at any given time, presents itself in only one way, but nature does not exclude the possibility that the object may appear in other ways. Heidegger argues that science cannot scientifically identify its own essence, and therefore cannot gain access to that aspect of nature that cannot be “gotten around”. For example, in order to talk about the essence of mathematics, one has to leave behind mathematical process, to focus on that which is inaccessible. It is only in focussing on the inaccessibility of that which cannot be outstripped by science that the essence of the phenomenon comes in to view.

Through this pointing to the inconspicuous state of affairs we are … directed onto a way that brings us before that which is worthy of questioning. In contradistinction to all that is merely questionable, as well as to everything that is “without question,” that which is worthy of questioning alone affords, from out of itself, the clear impetus and untrammelled pause through which we are able to call towards us and call near that which addresses itself to our essence. (Heidegger, 1977, pp. 179-180)

It is through reflection on that which is “worthy of questioning” that we arrive at a place that is part of the journey. Heidegger sees reflection not as being conscious of, or a knowing that belongs to, scientific endeavour, but as a journey towards the essential in all things.

The process of reflection is not static but changes in response to the place on the
journey where the questions arise and to the nature of that which emerges. This requires the researcher to be open to various levels of reflection, acknowledging that the researcher is connected to the journey they are on through their history and cultural orientations.

Reflection is needed as a responding that forgets itself in the clarity of ceaseless questioning away at the inexhaustibleness of That which is worthy of questioning – of That out of which, in the moment properly its own, responding loses the character of questioning and becomes simply saying. (Heidegger, 1977, p. 182)

Heidegger’s analysis of scientific methodology challenges its ability to explore the essence of phenomenon. There has been prolific research in the areas of psychosis, early intervention and treatment options, the majority of which has been undertaken using scientific methodology. The structure and processes of the methodology limit the descriptions of the experience of psychosis and treatment. Further, the diagnostic categorisation that exists within the scientific understanding of psychosis has its own limitations, which are currently being challenged. Using the concept of reflection, I intend to explore beyond the scientific object that is the signs and symptoms of psychosis, and journey towards the essential nature of hospitalisation for those young people with first episode psychosis. The concepts from Heidegger’s theory of Being and its application most germane to this study are provided in Chapter Four.

**Summary**

In this chapter, the historical conceptualisations of mental health over the centuries and how they have shaped our understanding of mental illness have been discussed. People who experience mental illness have been marginalised, stigmatised and
excluded throughout history, no matter what philosophical thought underpinned the conceptual models of the time. The experience of otherness, of being isolated, of being delegated to the realm of the irrational is one which has been projected through history and is evident in the mental health system today. In the latter part of this chapter, I have outlined the limits of such models to understanding the phenomenon of hospitalisation as experienced by young people with first episode psychosis.

According to Heidegger, we are thrown into the world, dealing with what it receives from the past. We are already part of the world as we are. We are shaped by historical and cultural understandings, but have the ability to make choices within that. We are pre-occupied with the world in the present and limited by the collective culture of the world that Heidegger calls the ‘Them-world’ (Heidegger, 1962). Gadamer writes about the tension that exists between historical consciousness and the tradition, and the present, insisting that interpretation must consciously bring out that tension (Gadamer, 1960/1975). It is important then, as background to this study, to explicate the impact that historical thinking about mental illness and contemporary conceptual models have on those who experience hospitalisation during their first episode of psychosis.
Chapter 3: Contemporary Debates and Understandings of Psychosis

Introduction

The current literature pertaining to first episode psychosis and its treatment is immense and complex, with multiple foci including early detection and intervention, biological and genetic markers, treatment protocols and pharmacological and psychosocial interventions. Nursing literature and research have focussed on this area to a lesser extent, with a strong emphasis on explicating nursing roles and interventions, relapse prevention and specific therapeutic interventions. There is a paucity of research that pertains to the understanding of young people who experience first episode psychosis and particularly their experience of hospitalisation. In the last chapter, I explored the history of madness and the conceptual understandings that influence collective attitudes towards people who suffer from mental illness. In reviewing contemporary literature relating to psychosis, I aim to situate this study in an historical and scientific context, and to investigate the nursing knowledge in this area. In order to do so, I selectively reviewed the literature relating to the diagnosis and treatment of psychosis and current nursing practice, and drew on literature from fields such as psychiatry, psychology, sociology and nursing.

Psychosis

Psychosis is perplexing both for those experiencing the disturbed thoughts, perceptions, emotions and behaviour, and for many researchers who have studied it for over one hundred years (Walton, 1995). In this section, key elements and controversies that arise in research into psychosis, and their relevance to this study,
are laid out to better comprehend the puzzling nature of this condition.

**Diagnostic criteria**

First described as a discrete category of illness by Emil Kraepelin in 1896, then renamed schizophrenia by Eugen Bleuler in 1911, the concept of schizophrenia is almost universally accepted despite agreement that it is ill-defined. Psychosis is defined in various ways, from the narrow definition being restricted to delusions and hallucinations that occur in the absence of insight into their pathological nature. A less restrictive definition also includes prominent hallucinations that the individual realises are hallucinatory experiences. Broader still is a definition that includes the positive symptoms of schizophrenia, including disorganised speech, and grossly disorganised or catatonic behaviour. The definition used in earlier classifications (DSM-II and ICD-9) is now seen as too inclusive and focused on the severity of functional impairment, so that a mental disorder was termed “psychotic” if it resulted in impairment that grossly interfered with a person’s capacity to function in ordinary life (Wilson, 1993). Finally, the term has been used in psychoanalytic circles to describe the loss of ego boundaries or a gross impairment in reality testing caused by the inability of the personality to tolerate emotional experience (Rustin, Rhode, Dubinski & Dubinski, 1997). While this definition is not generally accepted in broader academic circles, it has contributed to the psychotherapeutic treatment of children and adolescents experiencing psychotic levels of disturbance by focusing on the containment of emotional pain through the therapist’s ability to bear and transform emotional experience by giving it meaning.

The definition that is given to psychosis influences the assessment, treatment and care provided to those experiencing it. For the purpose of this study, I have brought
together a working definition from various sources (Reed, 2008; Forchuk, Jewell, Tweedell & Steinnagel, 2003). In doing so, I have tried to avoid using overly technical terminology, instead opting for a definition that is more descriptive of the experience. The following definition of psychosis is being used:

When a person’s perceptual and cognitive functioning includes the presence of delusions, hallucinations, disorganised behaviour, marked loose associations and emotional turmoil, the person is said to be psychotic. Psychotic behaviours impair the individual’s ability to think, respond, remember, communicate, interpret reality, behave appropriately, and meet the ordinary demands of life.

The term psychosis encompasses a number of diagnostic categories within the DSM-IV that are used to order and summarise the different symptoms of psychosis (van Os & Tamminga, 2007). They are divided into two categories: non-affective psychoses, including schizophrenia, schizophreniform disorder, psychotic disorder not otherwise specified, substance-induced psychotic disorder, delusional disorder and brief psychotic disorder; and affective psychoses, including bipolar disorder, schizoaffective disorder and major depressive disorder with psychotic features. The term ‘first-episode schizophrenia-spectrum disorder’ has also been used (Ohlenschlaeger et al., 2007). These categories are meant to refer to broadly defined syndromes rather than biological processes, however they have come to be perceived as “... natural disease entities, the diagnosis of which has absolute meaning in terms of causes, treatment, and outcome as well as required sampling frame for scientific research” (van Os & Tamminga, 2007, p. 861).

The use of the term psychosis when referring to early intervention in this area is significant. Studies indicate that a majority of first episode cases represent
schizophrenia or other schizophrenia-spectrum disorders (Edwards, Maude, McGorry, Harrigan & Cocks, 1998). However, at the time of the first episode, the course of the illness is not known and a definitive diagnosis is considered untimely. Schizophrenic illness usually begins in adolescence or young adulthood, and while men are more at risk between the ages of 15 and 24, women exhibit a higher incidence over the age of 40. The incidence rate of first episode psychosis is estimated to be 15 to 20 cases per 100,000. It is often suggested that approximately one percent of the population suffers from a schizophrenic illness at some time in their lives (Bleuler 1991; Torrey 1988). However there is debate about the accuracy of this figure given the problems with actual definition of the concept itself and the absence of accepted disease markers (Jablensky, 1993). In a recent study, the overall incidence rate of all psychotic disorders was 34.8 cases per 100,000. However, a significant and independent variation of incidence was also found in terms of age, gender, ethnicity and place. This suggests that environmental factors at both individual and community level has an impact on the cause of psychosis (Kirkbridge et al., 2006).

The definition of schizophrenia has become more tentative over time, with a strong focus being on the treatment of symptoms of the disease. In the last fifteen years, research has also focussed on identifying neurological soft signs (NSS), and their association with symptoms and neurocognitive functioning in those suffering from schizophrenia (Chan, Xu, Heinrichs, Yu & Wand, 2009), genetic markers (Chumakov et al., 2002; Chen & Faraone, 2000; Sun, Han & Zhoa, 2010), drug-related markers (Le Hellard et al., 2009) and biological markers of the disease (Tandon et al., 2000; Novikova, He, Ctrurfello & Lidow, 2006).

It is common to find reference in the literature to the “positive” and “negative”
symptoms of psychotic disorders. The positive symptoms are those that are not based in reality, such as delusions, hallucinations and thought disorder. The negative symptoms refer to those attributes that should be there, but are not, and result in symptoms such as lack of motivation, social isolation and blunted affect. It has been suggested that there are two subtypes of the schizophrenic illness, one dominated by positive symptoms, the other by negative symptoms (Torrey, 1988). However, there is little supporting evidence for this in the current literature.

Up until the mid-1990s, there was a strong emphasis on categorising schizophrenia into different types – catatonic, disorganised, paranoid, undifferentiated and residual – based on the predominant clinical picture. This diagnostic category was further divided into categories of acute, chronic, in remission, or acute exacerbation of symptoms in a previously remitted or chronic state. Thus, it was seen as important to identify the type and severity of the psychiatric symptoms as well as the time perspective. With the increasing debate about the absence of objective disease markers for the diagnosis of schizophrenia, and the cause (or causes) remaining unknown, the basis of these categorisations is questioned.

The emergence of psychosis during adolescence or early adulthood has the potential to cause major disruptions in the ability of the person to meet ‘normative’ developmental tasks. Social, academic, sexual and vocational challenges are influenced by the onset of psychosis. Family and other social relationships can suffer, and the family experiences significant distress (Addington, Coldman, Jones, Ko & Addington, 2003).

In the last two decades, there has been increasing debate about the basic assumptions underlying concepts such as schizophrenia and bipolar disorder as described by
Kraepelin over one hundred years ago, in particular about the positive-negative distinction in symptomatology. This has led to what has been termed a ‘paradigm failure in functional psychosis’ (McGorry, 1991). The emphasis on unitary explanatory concepts for disease processes resulted in a preference for uni-causal models as opposed to the complexity of multi-causal models. A close linkage is assumed between clinical syndrome and pathophysiology, and has resulted in a research strategy that is virtually uni-directional: “…the sequence of study is clinico-pathological, from syndrome to marker or pathophysiology” (McGorry, 1991, p. 45).

McGorry advocates for a ‘loose linkage model’ of disease conceptualisation in which a single disease process may result in a finite number of syndromes that may overlap in their clinical expression. While McGorry’s conceptualisation of psychosis as an umbrella for a number of related syndromes assists in addressing the limitations related to the use of the uni-causal model, it relies on the assumption that there is a one-to-one correspondence between symptoms and disease, and that pathophysiology itself can explain an illness. In addition, McGorry’s research is treatment focussed, identifying markers for the response to treatment rather than markers for the illness of schizophrenia.

**Research focus**

The assumption in scientific research of the close link between symptomatology and the underlying disease process led to a research strategy that is primarily focussed on pathology, identifying the biological markers related to treatment of the disease. The clinical reality of psychosis is not being challenged in this debate. However, the effect of imposing this unitary model of disease conceptualisation on to the diagnosis of psychosis is challenged, and a focus on addressing symptoms rather than diagnosis is recommended. The underlying inference in this recommendation is that addressing
the symptoms equals addressing the illness as experienced by the person. Indeed, clinicians are encouraged to carefully explore the “…explanatory model/s held by the patient for his/her recent problems and experience” with the primary purpose of finding a way to get the patient to accept treatment and support (McGorry, 1991a).

The biological and psychological symptoms experienced in first episode psychosis can only be understood in the light of the individual’s personal background meaning and the context of their lives, as a description of symptomatology does not adequately explain the experience of the illness nor provide a way in which clients are centrally involved in decision making regarding treatment.

More recently, the Genome-Wide Association Study (GWAS) and other case-controlled studies have found that only a small percentage of the genetic factors identified account for the heritability of schizophrenia (cited in Cuthbert & Insel, 2010). The variants that have been identified in these studies apply equally to other serious mental health problems such as bipolar disorder, unipolar depression and even epilepsy. This suggests that the Kraepelinian dichotomy between schizophrenia and bipolar disorder is further weakened. However, these Kraepelinian assumptions have become so embedded in understandings of psychotic illnesses and the policies and procedures that formalise this in practice, that studies that deviate from current thinking are not supported.

The National Institute of Mental Health in the USA is currently calling for a new approach to the diagnosis of psychotic disorders, one where researchers are encouraged to focus not on presenting symptoms, but on a range of functional domains including negative affect, positive affect, cognition, social processes and arousal/regulatory systems (cited in Cuthbert & Insel, 2010). Here in Australia,
recent significant increase in funding for both research into early psychosis in youth and services to that population was directed through one organisation. All applications for funding had to comply with that model of service delivery and research, thereby perpetuating current thought as opposed to expanding knowledge in this area (Department of Health & Aging, n.d.). Such a situation speaks to a politics of knowledge where one group fails to sustain itself and another succeeds.

In reviewing the literature regarding personality change and psychosis, the individual’s subjective experience of psychosis has generally been overlooked. The researchers claim that “…the findings from outcome studies do little to explicate the specific pathological processes in relation to the functioning of the individual that may contribute to … poor outcomes” (Hulbert, Jackson & McGorry, 1996). This view reflects the Cartesian notion that the mind and body are separate and can be studied independently, with more credibility being given to that which is perceived to be objective reality. Again, consideration of the context in which young people experience psychosis and receive treatment is an essential part of understanding their ‘subjective experience’.

The history of this ‘demeaning of experience’ in literature is traced back to the Renaissance when Galileo and Descartes demonstrated that all physical objects in the world could be quantified by mathematical formulae (Colaizzi, 1978). Science very quickly developed experimental methodologies to investigate inanimate objects and aspects of human existence that could be de-personalised, hence science’s emphasis on describing behaviour and symptoms rather than experience. The notion of viewing the human being as an object enabled huge advances in science and the understanding of disease processes following the Enlightenment, however when this
notion is applied to the study of human action, the results appear confusing and incomplete (Benner & Wrubel, 1989).

To date, there has been little research on the experience of hospitalisation for young people with first episode psychosis, and research into post-psychotic depression has focussed, in the main, on adults experiencing chronic schizophrenia. The methodologies used to investigate these issues have tended to be experimental, excluding descriptions that those with schizophrenia have given to their experience of depression.

In contrast to this form of research, Walton, in a phenomenological study, examined what it was like to live with a schizophrenic illness (Walton, 1995). Through interviews with adults living with schizophrenia, she explored the profound impact that the experience of chronic illness had on the participants’ sense of self. She found they were able to “…integrate their past into their present” by understanding the nature of their illness and recognising that care is needed to manage in their lives.

While there has been much written about the brain pathology, neuropsychology and neuropharmacological issues related to psychosis and post-psychotic depression, there is very little written about how young people experience the impact of psychosis and treatment on their lives. The common element in the research described above is the pre-eminence given to the quantifiable physical aspects of the diagnosis over experience. The assumption is that the diagnosis made by the expert fully describes the experiences these young people have of the illness, even while this diagnosis is viewed as negatively affecting their lives.
Phases of illness

First episode psychosis is seen as having four phases: prodromal, acute, early recovery and late recovery. The prodromal phase, which is usually identified retrospectively, is the period prior to the development of overt psychotic symptoms. The early warning signs include suspiciousness, depression, mood swings, sleep and appetite disturbances, social withdrawal, and perceptual and thought changes. These signs in and of themselves can be related to many life experiences, and they only take on significance if they are coupled with higher risk signs of family history of psychosis or specific developmental issues.

There has been much research into identifying and codifying early warning signs of psychotic illness or relapse. The difficulty with identifying prodromal symptoms of psychosis is that the criteria are vague and open to interpretation (Day, 2001). The DSM-IV (American Psychiatric Association, 1994, p. 282) documents the prodromal symptoms of schizophrenia as follows:

- Marked social isolation or withdrawal
- Loss of interest in school or work
- Deterioration in hygiene and grooming
- Markedly peculiar behaviours
- Blunted or inappropriate affect
- Odd thinking or magical beliefs
- Perceptual disturbances
- Disturbances of speech such as digressive or vague speech or poverty of speech
- Lack of energy or volition.
It is clear that all of the above ‘symptoms’ could just as easily describe normal adolescent behaviour and therein lies the problem faced in researching early interventions in psychosis.

A study of the prevalence of prodromal symptoms among high school students found high percentages of the students (39-51%) experienced symptoms such as magical thinking, unusual perceptual experiences, impaired role function and energy (McGorry, Mihapoulos, Harrigan & Jackson, 1996). This prevalence of classic prodromal features in adolescents indicates that either the prodromal features themselves are not enough to predict the onset of psychosis, or that the symptoms identified as prodromal features are not adequately refined to be of use in predicting the onset of psychosis. The fact that these features are so strongly related to adolescent development and behaviour is problematic, and suggests that any intervention at this prodromal phase is premature.

*The acute phase* is the time when the majority of people experiencing psychosis present for treatment. The symptoms include hallucinations, thought disorder and delusions. Hospitalisation is often required to keep the young person safe while antipsychotic medication is administered and monitored, and to manage environmental stressors that are impacting on the illness experience. The first six months following the acute treatment is seen as *the early recovery phase*; a time in which individual and family therapies focus on enhancing the remission of positive symptoms.

*The late recovery phase* occurs in the six to eighteen months following the early recovery phase, and the goal is to prevent relapse and promote full recovery. The overall goal of the recovery phase is to assist individuals to understand their illness
and to move towards their life goals (McGorry & Edwards, 1998).

**Duration of Untreated Psychosis (DUP)**

Psychosis is a major neurological trauma, and yet the time lag between the onset of psychotic symptoms and the start of treatment is often extensive. There is some evidence that suggests the longer the duration of untreated psychosis, the poorer the outcomes (McGorry et al., 1996). Research in this area often combines the time of untreated psychosis with the projected prodromal period to determine the duration of untreated illness (DUI). In a small scale case comparison of patients with schizophrenia who had experienced long (244 weeks av.) versus short (15 weeks av.) DUP, the onset for the long DUP group was insidious, with changes in functioning being less noticeable (Falloon, Coverdale, Laidlaw, Merry & Kydd, 1998). The concept of DUP and its effect on long term outcomes are used to bolster the case for increased services in the area of early intervention.

However, this association between long DUP and poor outcome is also seen as an effect of selection bias in studies. Research indicates that 25-50% of all psychotic–like conditions progress towards remission (Ciompi, 1980; Warner, 2005). Virtually all the studies that demonstrate the link between DUP and outcome include recent onset cases that are biased to include more ‘good’ prognosis cases and will have an overall better outcome (Warner, 2005), thereby skewing the results in favour of early intervention. In epidemiological terms, the positive predictive value of any test is dependent on the prevalence of the condition to which it applies. This means that for every individual who is appropriately treated for psychosis, there are many more with the same spectrum of symptoms who will never develop a chronic illness (Verdoux, 2001). While the fact that there is often a time lag between the onset of
symptoms and the start of treatment is not challenged, the significant impact of early intervention services reported in the research is challenged (Pelosi & Birchwood, 2003).

Given that the diagnosis of psychosis has become more tentative as research into the area progresses, and the symptomatology of the prodromal phase is problematic (particularly in adolescents), the predominant use of the scientific model to explore and validate this concept limits the understanding of the experience of early psychosis. Other social and cultural issues that impact on the experience of early psychosis include the cultural conceptualisation of health and mental health in operation in the community, the effects of stigma related to mental illness, the accessibility of services, and the knowledge of care providers, particularly primary care physicians.

**Critical period**

There is a substantial body of research addressing the issue of early intervention in psychosis. The early phase of psychosis (i.e. the first three years) is seen as a ‘critical period’ in which to impact positively on the social and personal disadvantage that develops aggressively during this time (Birchwood, Todd & Jackson, 1998). Apart from the significant research undertaken into the pharmacological and neurobiological advances in the treatment of psychosis, there is also an array of research into areas such as the use of Cognitive Behavioural Therapy, the importance of psycho-education, the impact on the family and the involvement of the family in treatment, the link between personality styles and prognosis, and the use of intensive home based treatments. One of the principles that permeate the early intervention discourse is the avoidance of hospitalisation due to its perceived negative impact on
the trajectory of the illness. However, there is evidence that there is no difference in treatment outcomes for young people who receive a high intensity community based service and those who are hospitalised in crisis (Henggeler et al., 2003).

Hospitalisation is linked with adverse secondary impairments. However, the question arises as to whether it is the actual hospitalisation or the experience of institutionalisation that has a negative impact on the trajectory of psychosis. The research into the secondary impairments and disabilities has, in the main, been undertaken in institutions with participants who have been diagnosed with chronic schizophrenia and who have been associated with institutions both as inpatients and outpatients for many years (Day, 2001; Birchwood, 1998). This presents a distorted view of the prognosis of psychosis. It is not surprising then that this research indicates that the main field of impairment in schizophrenia is not the clinical symptoms but social functioning, which would suggest a failure of rehabilitation rather than diagnosis. Given the population that has been studied, this raises the question as to whether this is actually an artefact of institutionalisation rather than a predictor of prognosis.

**Psychosis and PTSD**

First episode psychosis is a traumatic event that is linked with co-morbid symptomatology (anxiety, depression and Post Traumatic Stress Disorder), however this link is as yet unproven. The traumas associated with psychosis are related to one of three broad groups of experiences:

- the content of the psychotic symptoms;
- the pathways to care (e.g. police involvement, detention in a secure ward);
- the experience of treatment. (Jackson, Knott, Skeate & Birchwood, 2004)
Research demonstrates that posttraumatic stress disorder (PTSD) type symptoms characterise the postpsychotic phase for many people experiencing psychosis (McGorry, Copolov & Singh, 1989; Shaner & Eth, 1989; McGorry et al., 1991; Edwards, Maude, McGorry, Harrigan & Cocks, 1998). Hospitalisation and treatment experiences are generally perceived as distressing and potentially contribute to the experience of PTSD, however the overall emphasis is on the description and incidence of PTSD symptomatology (Shaw, McFarlane & Bookless, 1997). While some young people were included in Shaw et al.’s study, the impact of age related developmental issues was not considered. The major aim of Shaw’s work was to explicate the phenomenology of symptomatology rather than the phenomenology of hospitalisation itself. The use of semi-structured interviews and rating scales did not explore the meaning of the experience for the participants nor their beliefs about the impact it had on their recovery.

While there is a significant quantity of research regarding the experience of trauma relating to the content of psychotic symptoms and the pathways to care, particularly in relation to PTSD symptoms, little is known about the impact of the patient’s perceptions of hospitalisation and treatment on the experience of trauma or the trajectory of symptomatology (Jackson et al., 2004).

With regard to the experience of trauma, the rigid framework of the DSM-IV and the ICD 10AM influences the understanding of the traumatic experience of first episode psychosis (Jackson et al., 2004). The framework is as follows:

**DSM-IV Criterion A for diagnosis of PTSD**

The person has been exposed to a traumatic event in which both the following are present: (1) the person experienced, witnessed, or was confronted with an
event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others; (2) the person’s response involved intense fear, helplessness or horror. (American Psychiatric Association, 1994, pp. 427-428)

Jackson et al. (2004) found that first episode psychosis is a traumatic experience for some, and that the trauma is mediated by the person’s coping style and their appraisal of the traumatic situation.

The instruments used in the research (McGorry’s Modified Version of PTSD Scale, Impact of Events Scale, and Hospital Anxiety and Depression Scale) identified the level of stress experienced, the presence of intrusive memories or avoidant behaviours displayed. However, it did so within the current diagnostic criteria for PTSD, which the researchers have already acknowledged is rigid and of questionable benefit in trying to understand the experience of trauma in first episode psychosis.

In addition, while the researchers identify the lack of knowledge about the impact of the person’s experience of hospitalisation and treatment, there is no attempt to elucidate in any detail the participants’ experience of treatment beyond the identification of objective events (e.g. police involvement, detained in a secure ward) and a rating of the level of stress on a Likert scale. The data focussed on the “psychological factors” (i.e. individual factors) relating to the participants and “objective events” such as police involvement without addressing the relational aspects involved. Both the illness and the experience of it are problematised within the individual. There is no mention of the participants’ relationships with mental health professionals and the meaning the participants gave to these interactions, or of their relationships with their family and friends.
While the causal link between psychosis and PTSD has not been proven, some research has found that the participants’ appraisal of potentially traumatic events and their coping styles may mediate the traumatic impact of the first episode of psychosis (Jackson et al., 2001). The major emphasis of this research is on identifying coping styles that impact on the experience of trauma, focussing on individual characteristics to the exclusion of other issues that may impact on the overall experience of first episode psychosis. The experience of first episode psychosis occurs within a context. Family, friends, and mental health and other professionals are all part of that context, and their involvement requires consideration in understanding this experience.

**Early intervention in psychosis**

Early intervention in psychosis is viewed as having opportunity to impact on a number of outcomes:

- to limit or prevent distress;
- relapse rates;
- the impact of the stigma of mental illness (or the perceived negative outcomes);
- the coercive management previously accepted as required for people with chronic mental illness;
- suicide rates among people with serious mental illness;
- the social disadvantage experienced by many people with serious mental illness; and
- the economic costs associated with chronic mental illness (Birchwood, 2000).

The current models that explain early psychosis are based on variants of a stress-
vulnerability hypothesis. The onset of the illness, the severity of the illness, and the propensity for relapse are a reflection of the interaction between environmental stressors and biological vulnerability due to genetic predisposition (Norman & Malla, 1993a; Norman & Malla, 1993b; Tandon et al., 2000). Environmental stressors include issues at home or school and substance misuse. The protective factors identified within this model, including appropriate social supports, positive premorbid coping skills, and appropriate medication can assist in reducing vulnerability and moderate the impact of stressors.

The case for early intervention is not universally accepted, although most would agree that aggressive treatment of first episode symptoms with antipsychotic medication, psycho-education and management of stress actively reduce the negative outcomes of the acute illness (Wyatt & Henter, 2001). Much of the research promoting the benefits of early intervention in psychosis has been undertaken with people who have become symptomatic within two years of their participation in the research. Indeed, the majority of the research involves participants within twelve months of their diagnosis with psychosis (Warner, 2005). This is problematic because while the acute and early recovery phases of the illness last for approximately six months, the late recovery phase can last for up to two years. Recent research indicates that the outcomes of early intervention in first episode psychosis previously documented, in which participants were involved in a specialised, intensive intervention, are not markedly different at five years from those who received ‘standard’ treatment. The extent to which the benefits persist after two years is unclear (Gafoor et al., 2010; McCrone, Craig, Power & Garety, 2010). One inference to be made from this data is that the effectiveness of the intensive intervention is only maintained as long as the intensive treatment continues. Once it
ceases, the benefit slips away.

A recent proposal for a “Psychosis Risk Syndrome” to be included in the yet to be released DSM-V aims to identify those at risk of developing psychosis and treat them with cognitive therapy and antipsychotic medication before the onset of psychotic symptoms. This has been strongly challenged as a “...prescription for an iatrogenic public health disaster” due to the lack of evidence that antipsychotic medications or cognitive therapy are effective in preventing psychotic episodes (Frances, 2010).

**Treatment of First Episode Psychosis**

The treatment of first episode psychosis, as outlined in clinical guidelines provided by organisations such as the American Psychiatric Association (APA) 2004 and the National Institute for Health and Clinical Excellence (NICE) 2009, are based on a number of common principles, including:

- the competence of health care professionals to facilitate access and sustained engagement in low-stigma settings not only for the young person presenting with symptoms of psychosis but also the family;
- working in partnership with the individual and carers in negotiating treatment decisions;
- the capacity of mental health services to work in partnership with local key stakeholders in order to address the holistic needs of the client such as education, occupation and housing;
- the early identification and assessment of frank psychosis;
- the provision of psychological interventions such as cognitive behaviour therapy, psycho-education and family interventions to commence in the acute phase of treatment; and
all treatment and care should take into account individual people’s needs and preferences; and that treatment and care should be offered with hope and optimism (APA, 2004; NICE, 2009).

The aims of treatment of first episode psychosis are four-fold:

- to reduce time between appearance of symptoms and initiating therapy;
- to accelerate remission and prevent relapse;
- to use both biological and psychological measures; and
- to maximise client’s ability to get back to normal life.

**Early detection and assessment**

It is generally accepted that the early identification and treatment of psychosis is a key element of outcome success. As the early symptoms of psychosis can be confused with a number of other medical and psychological problems, and indeed with normal adolescence, a strategy identifying pathways from the onset of psychosis to successful engagement with specialist services is vital. This requires a strengthening of links between primary care, where most young people first attend, and secondary services for young people with serious mental illness (Spencer, Birchwood & McGovern, 2001).

**Therapeutic engagement**

While there has been little systematic study of engagement in first episode psychosis, it is generally agreed that this involves finding common ground with the client and family, avoiding confrontation of their explanatory models of illness early in the relationship, and delivering services in as flexible a manner as possible (Birchwood,
Fowler & Jackson, 2000). The allocation of a key worker who remains consistent during the critical period is an important element of developing a trusting and positive relationship. As nurses make up the majority of the workforce in mental health services, it is assumed that this role would fall primarily to nurses, particularly in inpatient settings, but this is not documented in the research.

**Comprehensive assessment**

A full assessment of mental state, risk and biological, psychological and social vulnerabilities and stressors is considered an essential aspect of the management of first episode psychosis (Spencer, Birchwood & McGovern 2001). This assessment not only involves the traditional psychiatric assessment, mental state examination and physical investigations such as EEG and ECG, but also includes the client and family’s understanding of what is happening, their access to services, and the social needs and strengths of the client and family. Gaining an understanding of the social stressors that the young person may be encountering provides important information to be taken into account when developing a treatment plan. There is a level of diagnostic uncertainty involved in assessment of the first episode of psychosis because many of the symptoms reflect normal adolescent behaviour. Precipitate diagnosis is found to be associated with pessimism in staff, families and young people, which in turn can have a negative impact on the course of the illness (McGorry, 1995).

**Treatment**

Following the exclusion of organic causes, the treatment of psychosis is recommended to take place in the least restrictive environment possible. This is based on the link that is drawn between PTSD symptomatology and hospitalisation...
A phenomenological study of hospitalisation for young people with first episode psychosis

during an acute episode of psychosis (McGorry et al., 1991). However, as discussed above, this link has not been proven, even though it is acknowledged that a young person’s first experience of an acute psychiatric ward may be distressing, particularly if that ward is in the adult mental health system.

The Lambeth and OPUS studies have found that while specialised early intervention services reduce the risk of hospitalisation and improve outcomes in the first one to two years, there is no evidence that these improved outcomes are maintained in the longer term, particularly after the specialised service is withdrawn (Gafoor et al., 2010; Nordentoft et al., 2010).

Both pharmacological and non-pharmacological treatment approaches are documented in the literature. In most cases of first episode psychosis, antipsychotic medication is the first line of treatment, with psychoeducation, family involvement and Cognitive Behaviour Therapy (CBT) enhancing the outcomes.

Antipsychotic medication is used in first episode psychosis to induce remission with the lowest dose possible while minimising adverse effects. These medications are generally divided into two categories: typical antipsychotics and the newer atypical antipsychotics. Typical antipsychotics include haloperidol, pimizode and chlorpromazine. The newer, atypical antipsychotics include olanzapine, risperidone, quetiapine and clozapine. Current evidence suggests that all these medications are equally effective in controlling the positive symptoms experienced in a first episode of psychosis (Centre for Addiction and Mental Health, 2009). All antipsychotic medications have unpleasant adverse effects, however they differ from one another in terms of these effects and, as a result, some medications are better tolerated by some people and other medications are better tolerated by others. Common adverse
effects include:

- anticholinergic effects\(^1\) such as dry mouth, blurry vision and constipation;
- central nervous system effects such as sedation and extrapyramidal side effects (dystonia, akathisia, Parkinsonism)\(^2\);
- cardiovascular side effects such as tachycardia\(^3\), dizziness and syncope\(^4\);
- endocrine side effects such as hyperprolactinemia, galactorrhea, secondary amenorrhea, gynecomastia, decreased libido and impotence\(^5\);
- metabolic side effects such as weight gain and associated illnesses such as diabetes and cardiac disease;
- the most severe adverse reactions are tardive dyskinesia\(^6\) and neuroleptic malignant syndrome\(^7\).

Clozapine is generally used for treatment resistant psychosis and as such is rarely used in first episode psychosis. It has additional significant adverse effects of agranulocytosis\(^8\) and seizures.

Benzodiazepines or minor tranquilizers such as lorazepam and alprazolam are used in the treatment of hostility due to their absence of extrapyramidal side effects.

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1. Anticholinergic effects refer to those resulting from blocking of the neurotransmitter acetylcholine.
2. Extrapyramidal side effects are marked by abnormal involuntary movements, alterations in muscle tone (dystonia) and postural disturbances. Akathisia refers to motor restlessness and anxiety. Parkinsonism refers to a disorder that manifests the symptoms of Parkinson’s Disease including mask-like face, a tremor of resting muscles, muscle weakness and peculiar gait.
3. Tachycardia – an abnormally rapid heartbeat.
5. Hyperprolactinemia is an excessive amount of prolactin in the blood which in women is usually associated with secondary amenorrhea (when menstruation has begun and then ceases) and galactorrhea (persistent secretion of milk irrespective of nursing), and gynecomastia (excessive development of mammary glands), decreased libido and impotence in men.
6. Tardive dyskinesia – impairment in the power of voluntary movement resulting in an often irreversible series of involuntary movements of the tongue, lips, jaw or fingers.
7. Neuroleptic malignant syndrome – a rare but potentially fatal syndrome involving tachycardia, tachypnoea (rapid slow breathing), fever and muscle rigidity.
8. Agranulocytosis – an acute disease in which there is a sudden drop in the production of leukocytes, leaving the body defenceless against bacterial invasion.
While antipsychotics are the first line of treatment in first episode psychosis, there are a range of psychosocial interventions that focus on psychological adjustment, and maintenance of relationships and social roles. Denial of the illness can lead to non-compliance with medication, while pessimism regarding future orientations and self agency can be related to an overt acceptance of the illness and the attached stigma (Birchwood, Todd & Jackson, 1998). Psychosocial interventions such as psycho-education and CBT can assist the young person experiencing psychosis to recognise and take control of the symptoms, and to challenge the stereotypes and discrimination in the community.

Social relationships and the environment in which these relationships occur are decisive factors in recovering from psychosis (Schon, Denhov & Topor, 2009). Environments that are dominated by anxiety or aggressiveness impact negatively on recovery rates. Social relationships with peers, whether at school or at work, are very important to young people. They increase self-esteem and positively influence recovery from psychosis (Warner, 1994). An important aspect of treatment in first episode psychosis is the psychosocial support provided to maintain social relationships, even in the acute phase of the illness.

**Family focus**

Since most first episodes of psychosis occur during adolescence, many of these young people will be living with family members or partners. Involvement of family and psycho-education in schizophrenia has been shown to delay psychotic relapse for up to two years (Birchwood & Spencer, 1999). Much of the research into family interventions has been focussed on families with high expressed emotion (EE). The
hypothesis is that a person who has experienced psychosis who lives in a family where there is high expressed emotion, judged by criticism, over involvement and hostility towards that person is more likely to relapse than one who lives in a low EE family (Hirsch & Bristow, 1993). There has been much debate about the link between EE and relapse, and whether high EE is a reaction to a family member experiencing psychosis rather than its cause. Recent literature suggests that the concepts of trauma and loss are more useful in guiding family interventions in early psychosis, with direct focus on exploring and reducing the negative experiences of parenting in the early stages of psychosis in order to prevent a problematic family dynamic later (Birchwood & Spencer, 1999).

**Relapse prevention**

The cumulative experience of the positive symptoms of psychosis is associated with negative long term outcomes for those who experience psychosis (Wyatt, 1991), so the prevention of relapses potentially changes the long term outcome of psychosis. The basis of relapse prevention is the modification of stress and vulnerability factors through the use of pharmacological and psychotherapeutic interventions. Using a stress-vulnerability framework, clients and their families, in conjunction with the clinician, are encouraged to develop a relapse prevention plan to identify the unique warning signs of psychotic relapse and prepare a response to these. This response involves pharmacological interventions, individual coping strategies, psychotherapeutic resources available through the mental health system, and drawing on family and community resources.

**Nursing Interventions in First Episode Psychosis**

The contribution of mental health nurses in the care and treatment of young people
with first episode psychosis, while not being addressed in the clinical guidelines
directing practice in this area, is being discussed in nursing literature and research.
The research literature, in explicating the specific nursing interventions employed by
mental health nurses in the treatment of psychosis, identifies a number of factors that
are reflective of generic mental health nursing, and indeed may be shared by other
professional members of the care team.

**Therapeutic relationship**

Establishing a trusting, reciprocal and supportive relationship is essential for helping
people experiencing their first episode of psychosis (Forchuk, Jewell, Tweedell &
Steinnagel, 2003; Freeman, 2002; McCann & Baker, 2001). Some of the strategies
used by nurses to establish this relationship include tuning in, friendliness,
maintaining confidentiality, attempting to understand and being there for the client.
Through an effective therapeutic relationship, the nurse can foster the young person’s
hope for the future and their sense of agency in recognising and managing their
illness, as well as alleviating anxiety and confusion (Reed, 2008). The therapeutic
relationship built on trust and client-centred goals is seen as the cornerstone of care
in mental health nursing (Reed, 2008). However, the quality of the evidence in
nursing research in relation to therapeutic relationships is limited (van Dusseldorp,
Goossens & van Achterberg, 2011).

**Relapse prevention**

Nursing research, in line with the practice guidelines discussed above, also identifies
relapse prevention as an important aspect of the mental health nurse’s role. Nurses
play a central role in the development of relapse prevention plans. Aspects of such a
plan include education regarding positive and negative symptoms, the consequences
of substance misuse, awareness of early warning signs and stressors, and the development of coping strategies (van Meijel, van der Gaag, Kahn & Grypdonck, 2006). The relationship between the nurse and the client, and the client’s motivation and understanding of their illness is enhanced through the development of the relapse prevention plan (Stevens & Sin, 2005).

**Enhancement of social functioning**

The experience of first episode psychosis has a negative impact on young people’s achievement of their developmental milestones and their social functioning (Waldheter et al., 2008). Specific psychosocial interventions aimed at supporting and improving social functioning are among those interventions that mental health nurses identify as part of their role, however, very little of the nursing literature on nursing interventions focusses specifically on first episode psychosis. Interventions discussed include social skills training (Gillam, 2002; Rogers, 2006), psychoeducation (van Meijel et al., 2003) and training in coping skills (Renwick et al., 2009; Sin, Taylor & Kendall, 2009). The application of CBT by mental health nurses has also been found to aid recovery in first episode psychosis by increasing recognition of stressors and coping abilities (Waldheter et al., 2008), however nursing is not the only profession to use such techniques. CBT is a therapy that helps clients discover and overcome distorted thoughts that cause psychological distress. While prolific research into CBT has documented the potential of the techniques, it has also been challenged as unable to explore the unconscious or emotions, and only explores the past in a limited way. In addition, it places the therapist as the source of intelligence about the problem rather than accessing the client’s expertise in their own life. Despite this, nursing research indicates that nurses play a lead role in helping the client to identify their needs and strengths, to re-connect to previous activity (e.g. study or work), and to
establish hope for the future (England, 2006; Sin et al., 2009; Rogers, 2006).

**Integrated treatment**

First episode psychosis has a significant impact on the family and carers of the client. Research shows that optimal outcomes are achieved when family/carers are involved in the treatment (Mullen, Murray & Happell, 2002; Jeppesen et al., 2005). Nurses are involved in providing psychoeducation to clients and family/carers to increase their understanding of psychosis and its treatment, and to explore their resources and skills in living with the illness with confidence (Kilkku, Munnukka & Lehtinen, 2003).

**Medication**

Antipsychotic medication is the most common treatment for first-episode psychosis, and nurses are responsible for the administration of this medication during hospitalisation and monitoring the effects and adverse effects. They work with the client to enhance compliance with medication regimes through psychoeducation, the establishment of relapse prevention programs and discharge planning (Barker, Lavender & Morant, 2001; van Meijel et al., 2006). This requires a positive therapeutic alliance so that nurses understand the reasons why clients may not want to take medication and to use their skills to lessen this difficulty.

**Discharge planning**

Research indicates that nurses are also involved in discharge planning, ending the therapeutic relationship in a positive manner, referral to community services and support with the transition back to ordinary life (Rogers, 2006; Etheridge, Yarrow & Peet, 2004). The aim of good discharge planning is to provide the client with the best possible chance of avoiding relapse. The reduction in the length of stay in recent
years has had an impact on the extent to which effective discharge planning can be achieved. The main purpose of hospitalisation in first episode psychosis is now the reduction of positive symptoms, and clients and families are still dealing with the shock and trauma of the psychotic episode at the time of discharge. The extent to which nurses can provide effective psychoeducation and develop a comprehensive relapse prevention program during short term hospitalisation is limited, and these roles are often taken up by clinicians providing community based care.

Summary

This chapter has explored the contemporary understandings of first episode psychosis, and the challenges and debates that have arisen in the research. While the dominance of scientific and biological research in recent times has led to a greater understanding of brain pathology and neurological aspects of psychosis, the definition of psychosis and schizophrenia has become more tentative over time. The unitary model of disease conceptualisation driven by Kraepelinian assumptions has made it difficult to undertake research that diverges from current thinking, with “the inertia of diagnostic orthodoxy exert[ing] a powerful hegemony over any alternative approaches...” and resulting in much debate (Cuthbert & Insel, 2010, p. 1061).

The concept of early intervention in first episode psychosis has been a strong influence on clinical practice since the 1980s. The recent debate about proposed interventions before the onset of psychosis (for those having identified risk factors) has intensified the debate about the whole concept of early intervention as opposed to the need for high quality, long term interventions that are flexible enough to meet the needs of individuals experiencing psychosis and their families.

Discussion in this chapter has referred to the struggle in nursing research to articulate
the contribution of mental health nursing to the assessment and treatment of first episode psychosis. There is evidence in the research that the therapeutic relationship based on trust and equality is the basis for all other nursing interventions. Nursing research has been influenced by biomedical trends in psychiatric research into first episode psychosis, with several recent studies focussing on the use of quantitative measures to assess levels of recovery and the use of CBT to aid relapse prevention. However, the majority of nursing research has used narrative reviews and qualitative measures to explore the relational aspect of nursing practice in first episode psychosis.

This chapter has provided a context in which the present study sits amidst extensive research literature regarding psychosis and major debate about the primary underpinnings of the diagnostic categorisation itself. Few studies exploring hospitalisation as experienced by young people with first episode psychosis were found, and as this experience influences the assessment and subsequent interventions, there is clearly a need for further qualitative research in this area. The pertinence of the phenomenological approach to this study and the method used will be discussed in Chapter Four.
Chapter 4: Methodology

Introduction
The discussion in the previous chapter has focussed on the research context surrounding first episode psychosis and the nursing contribution to assessment and treatment. The purpose of this chapter is to discuss the use of phenomenology as a research method in the exploration of hospitalisation for young people with first episode psychosis, the way in which the study was carried out and the process of analysis of data.

Phenomenology has been described as “...the study of the movement of consciousness through time – including the way things appear to us” (Borgerson, 2010, p. 78). The aims of a phenomenological study are very different from those of natural science in that it does not aim to identify causal factors, explanations or categorisations, but to explore a deeper understanding of a phenomenon and how it is connected to human existence rather than an empirical truth. In order to identify the phenomenon of hospitalisation as experienced by young people with first episode psychosis, I will draw considerably from the works of interpretive phenomenologist Martin Heidegger, particularly his early work Being and Time (1962). The writings of contemporary feminist phenomenologist Kelly Oliver have also contributed to the analysis of the data and to my formulations here. I will be focussing on the concepts of Heidegger, Gadamer and Oliver that are germane to the findings of the study.

Heidegger was primarily concerned with human existence in the world. “Being-in-the-world”, relating to things and other people in everyday situations, is constitutive of what it is to be. So it is our everyday interactions with people, the goals we have
for our lives and the way we live them out that defines us. Although we are in the
d world and our first-hand understanding of it comes by way of participation and
practical concern rather than theoretical observation, we still have to inquire in to this
question of Being (Heidegger, 1962). The philosophy of phenomenology asserts that
this is what distinguishes human beings from all other entities.

Heidegger’s fundamental project is one of understanding the nature of Being as
expressed through the being and action of human beings. In his analysis of the
human being, Heidegger is searching for the manifestation of Being. “Understanding
of Being is itself a definite characteristic of Dasein’s Being.” (Heidegger, 1962, p.
32). Heidegger’s project is not ontic in nature (i.e. related to the day-to-day existence
of human beings), but ontological (i.e. related to the Being of human beings).
Heidegger’s ideas about what it means to be a person are central to an understanding
of the phenomenological approach to a study. It guides how the research question is
asked and how it is answered.

In Heidegger’s view we are not just beings in a world of other beings. We are not
simply located in the world, but are united with it through our relationships with
others, our work, our connection to the environment, and so on. The human self and
the world are considered one. Therefore we are shaped by the culture and the
historical environment in which we live, and at the same time are able to choose how
we respond to our history and our culture. Such a view would mean that the ideas
and values that a community may have regarding young people who experience
mental illness will influence the way in which a young person will see themselves in
the light of that experience.
Intentionality

The first and fundamental rule of the phenomenological method is intentionality. Every act of consciousness and every experience that we have is intentional; that is we are conscious of or have an experience of something. The phenomenological concept of intentionality goes against the ordinary use of the word. Intentionality is not about planning or the purpose we have in mind when we act, but about reaching into (just as ex-tending is reaching out from).

In the empiricist (such as Cartesian and Lockean) tradition, consciousness is presented as a blank slate, passive and empty. When we are conscious, we are in the main conscious of ourselves, our actions or our ideas (Sokolowski, 2000). All cognition occurs in the brain and our states of consciousness are all that we can be truly certain of. This distinction between the subjective and the objective has pervaded scientific research in our culture, to the extent that the majority of research in to aspects of mental illness is based purely on biological, scientific constructs.

In phenomenological thinking, subject and object are not the same, but they are considered to be inextricably bound together. The subjective experience cannot be adequately described in isolation from its object. Phenomenological investigation then seeks to inquire into the connection between the subject and the object. In order to undertake this investigation, we need to abandon the natural position with which we interact in our day-to-day lives, in which the world is the “… horizon or context for all things that can be given…” (Sokolowski, 2000). The phenomenological attitude disengages with the natural attitude in all its forms and becomes reflective of that which lies within our day-to-day lives, including the thinking that underlies our actions and experiences.
**Temporality**

Phenomenology has developed a highly articulated theory of time and temporal experience. Time pervades all things and plays an important role in the establishment of personal identity. In phenomenological thinking, there are three levels of temporal structure. The first is world time or objective time. This is the time of clocks and calendars, time that can be related to the spatiality of the world. “The time being measured is located in the world, in the common space we all inhabit” (Sokolowski, 2000).

The second level is internal or subjective time. Internal time is not public, but relates to the events of conscious life and the duration and sequencing of thoughts and experiences. There are sequences in internal time as one experience takes place before, after or at the same time as another, but this is not measured using clocks or calendars. While we experience one event as before or after another, we do not time the *experience* of the event in terms of the spatiality of the world. The way in which intentions and feelings are ordered, both in relation to one another and to present experiences, occurs in internal time.

The third level of temporal structure is the consciousness of internal time. The second level in itself is not enough to account for the awareness of internal temporality. This third level of temporality is pivotal to being able to consider things as phenomena.

The domain of internal time consciousness is … the origin of the deepest distinctions and identities, those that are presupposed by all the others that occur in our experience. (Sokolowski, 2000)

Heidegger differentiates between time and temporality. The word “time” refers to the
world, or objects within the world, or even the one who knows and the object that is known. Temporality, in Heideggerian terms, refers to our Being-in-the-world. It is part of human existence. It is through our everyday experience with things in the world, with other people, in our goals and intentions, that we are defined. According to Heidegger, we are thrown into the world, dealing with what the world receives from the past. We are already part of the world as we are. The situations into which we are thrown have future possibilities, an ability-to-be, but also limitations. We are pre-occupied with the world in the present, dealing with its concerns that are ready-to-hand and limited by the collective culture of the world that Heidegger calls the Them-world. We are shaped by historical and cultural understandings, but have the ability to make choices within that.

Time therefore is not lived as quantifiable linear time, rather we have its being in all three temporalities: its past, its possible futures and its present. Heidegger also relates temporality to the whole of the human being, from birth to death, and to the concept of care. Care is the concept that unifies our being-in and being-with the world, bringing together its projections or possibilities, that which limits those possibilities, and that which binds us to the world. Care is not an ethical term, but refers to all that matters to us, all that concerns us, all to which our attention is turned. This includes solicitude both for ourselves and others.

**Interpretation**

Hermeneutics is the theory of interpretation, named after Hermes, the messenger of the Greek gods and interpreter of messages for mortals. In Heidegger’s view understanding of the world is gained by interpretation. “In interpretation, understanding does not become something different. It becomes itself” (Heidegger,
1962, p. 188). When we encounter something, we identify it, name it, describe it as something, and in doing so, we understand it for what it means in our environment and how we relate to it. What we interpret is not so much our environment as a whole, but specific items within it, and also ourselves as we relate to this.

In interpreting, we do not, so to speak, throw a ‘signification’ over some naked thing which is present-at-hand, we do not stick a value on it; but when something within-the-world is encountered as such, the thing in question already has an involvement which is disclosed in our understanding of the world, and this involvement is one which gets laid out by interpretation. (Heidegger, 1962, pp. 190-191)

Gadamer (2004) goes further, saying interpretation is the process of interrogating the text, asking questions of it based on our own cultural context. He argues that there is no single correct interpretation of a text and there is no foolproof method of interpretation that leads to truth.

The explication of the fore-structure of understanding is the start of the phenomenological process of “making manifest that which manifests itself” (Heidegger, 1962, p. 189). Whenever we interpret something we rely on our prior understanding, on our assumptions about the phenomenon. Interpretation depends upon prior understanding and understanding depends on interpretation. Within this circle lies “… a positive possibility of the most primordial knowing” (Heidegger, 1962, p. 195). Gadamer refers to these preconceptions that an interpreter of a text brings as “prejudices” and the process of uncovering and testing those prejudices occurs mainly through our interactions with other people, such as in research. He defines these prejudices as the historical or traditional ways in which we experience
something and what that encounter says to us, and these prejudices can play a positive role. As with Heidegger, Gadamer argues strongly that these preconceptions could or should be expunged, saying that legitimate prejudices should be acknowledged and inappropriate ones confronted (Gadamer, 2004).

Heidegger regards affective states as being constitutive of a fundamental criterion of being. He describes moods as lighting up our Being-in-the-world in very basic ways, revealing how we are attuned to our environment. They are not just subjective emotions, but provide an appreciation, from the inside, of the situation in which we find ourselves. Affective states light up a situation where there may be many ‘givens’, some of which are determined by an outside force and some of which are related to our past choices. In the world we are thrown into situations where there are many possibilities and limitations. Affective states light up the actual situation in which we find ourselves, and where we have come from and where we are going sit in the background in our focus on Being-in-the-world in that moment.

Witnessing

The phenomenological concept of witnessing has been formulated in the post-Heideggerian years. Witnessing is defined in two distinct ways: the legalistic term of being an accurate eyewitness, and the act of bearing witness to something that speaks to the essence of humanity. It is this definition of witnessing that Kelly Oliver, a contemporary philosopher in the feminist and phenomenology traditions, explores to move beyond the recognition of that which is privileged by the dominant culture, and to see the other not only as different, but to give those that are marginalised a space from which their agency is made evident. It acknowledges the invisible, “...what our eyes cannot witness...” (Oliver, 2001, p. 210). The potential of witnessing is not
simply to provide testimony of another’s experience at a given time in a visual way, but to be a companion and co-being that does not rely on immediacy or closeness. Oliver claims that subjectivity is developed and sustained by the ability to address others and be addressed by others, and the ability to respond to others and oneself (Oliver, 2004). The concept of witnessing, which moves beyond observation and recognition, will be explored in more depth in Chapter Seven where the role of observation in mental health nursing is compared to the impact that the ethical stand of witnessing the subjectivity of others.

In understanding the phenomenon of hospitalisation as experienced by young people with first episode psychosis, I will be listening with intent to the stories of the situations in which they find themselves. While asking about their current experience, I will also hear about issues relating to the past and the future, for any moment in the present is a crossing point for the past and the future (Dostal, 1993).

**Phenomenology and Nursing**

Nursing researchers have adopted the phenomenological approach to investigate many questions in the discipline of nursing and numerous nurse researchers have used the method (Beck, 1992; Benner, 1985; Madjar, 1991; Munhall, 1989; Wynn, 2002, 2006 & 2009). It has also been suggested that phenomenology emphasises the subjective reality in human experience and provides a way into issues that are not easily seen or quantified can be investigated (Munhall, 1989). The relationship between researcher and participant in phenomenological research is seen as reflecting the importance given to the nurse-patient relationship in clinical nursing (Thorne, 1991).

[It is nursing’s] concern with the experience of illness rather than the diagnosis.
and cure of disease, and its emphasis on health as well as illness, in many ways depends on an understanding of subjective experience. (Walton, 1995, p. 82)

The way in which nursing researchers have used phenomenology has been soundly criticised by Crotty (1996) as missing the point. The emphasis by nursing researchers on shared experiences and common meanings ignores the phenomenological edict to look beyond the subjective meaning of everyday life to the objective phenomenon to which the meaning is attached. Phenomenology pursues not the sense people make of things, but what they are making sense of (Crotty, 1996). Both Heidegger and Gadamer argue that subjectivity only exists in relation to the object and therefore cannot be separated from it. To escape the dualism of subjectivity-objectivity, phenomenological inquiry employs strategies to put common meanings aside in order to be open to the phenomenon, both its object and its subject, as it is.

The fundamental concept of intentionality is often misinterpreted in nursing phenomenology. It is used in the mundane, purposive sense of the word, rather than the link between the subject and the object. Crotty argues that nursing phenomenology is concerned essentially with the subjective and fails to inquire in to the meaning that is inherent in the object as this relates to the subject.

One of the major characteristics of phenomenological research in its traditional form is the attempt to get behind everyday acceptance of the world, behind the taken-for-granted meanings attributed to Being-in-the-world. The aim is not to explore the everyday, but to problematise it.

Crotty’s criticism of what he calls ‘nursing phenomenology’ is that it views phenomenology as the collated and synthesised essence of the subjects’ experiences. He claims that the mode of data collection and analysis ensures that the phenomena
is described in terms of the significance it has for the subjects individually, virtually guaranteeing them the data they are seeking (Crotty, 1996). According to Crotty the focus in nursing research (conducted with a phenomenological approach) on identifying themes and arriving at ‘comprehensive descriptions’ of the phenomenon has the potential to stop the researcher from studying the objectivity that is to be found in the subjective. The human experience speaks to something that is beyond itself, to what it is that is experienced (Crotty, 1996).

Crotty’s main criticism is of Dreyfus’s (1994) interpretation of Heidegger’s philosophy on which much of Benner’s and other nursing research is based. Dreyfus’s interpretation focuses on the first Division of Being and Time. Johnson (2000) argues that understanding temporality is the key to expanding the usefulness of Heideggarian phenomenology in nursing research. There are many examples of the application of phenomenology to nursing research that do not comply with Crotty’s critique. Scholars such as Bishop and Scudder (1997), Koivisto, Janhonen and Vaisanen (2002), Wynn (2002, 2006, 2009), and Yegdith (2000) have all successfully applied continental phenomenology in very different fields of nursing.

**Researching Young People**

There has been a significant change in the last two decades in the health priorities for young people, with a recognition that self-harm, substance misuse and depression account for a higher burden of disease than physical illness (Claveirole, 2004). As discussed in Chapter Three, it is also recognised that low prevalence illnesses such as psychosis account for a significantly higher percentage of the health budget than the prevalence indicates.

The risks of involving young people in research vary, ranging from potentially major
side effects from experimental therapeutic interventions to minimal-risk for participation in descriptive studies or health surveys. Minimal-risk research is described as research in which the risk of harm is “…not greater than ordinarily encountered in daily life during performance of routine physical or psychological examinations or tests” (Weber, Miracle & Skehan, 1994, p. 44).

Different beliefs and perceptions about the nature of childhood have lead to different approaches to seeking young people’s views. Similarly, different beliefs and perceptions about the nature of mental illness have influenced the ways in which researchers have sought to involve young people experiencing mental illness in research.

Traditionally, research has focussed on the development of the young person, who only reaches full legal status as an adult. This has shaped research that focuses on human development and collects data from adults involved with the young person or by observation and other methods where the young person is passive and the researcher/adult interprets their behaviour (Balen, Holroyd & Wood, 2000). This form of research has contributed significantly to our knowledge of child behaviour and development.

Discussions regarding the ethical dilemmas associated with this form of research are often dominated by a conceptualisation of young people as ‘vulnerable’ and in need of protection, as objects rather than subjects of research (Morrow & Richards, 1996). Within this paradigm, young people experiencing serious mental illness are considered to be particularly ‘vulnerable’ due to what is seen as their decreased capacity to reason, and they are thereby less competent. Conceptualising young people as less competent has “…provided teachers and parents with powerful
normative models of what children are (or should be) like. It reflects a cultural reluctance to take children’s ideas seriously … [and a tendency] to devalue children’s acts as a matter of course” (Morrow & Richards, 1996, p. 98).

An alternative approach to research with young people sees them as having genuine competencies that are different, but no less valid than those of adults (Claveirole, 2004). According to this model, young people are a reliable source of information about their own experiences. There is still significant debate about the importance of involving young people directly in research and enabling them to interpret their own information, and doing research ‘with’ them rather than ‘on’ them.

It is not uncommon in our society to believe that the experience of a mental illness encapsulates the person and is the dominant narrative for those experiencing it. Hence, we talk about a person being a ‘schizophrenic’ rather than experiencing schizophrenia. In doing so, the competency of the young person experiencing schizophrenia is being questioned as their capacity to reason is impaired by their mental illness.

Fundudis (2003) suggests that, in addition to recognising that age and cognitive functioning are often sufficient indicators of competence, an assessment of emotional maturity (including mental state, mood stability, attachment relationships and educational progress) and socio-cultural factors (family values, and religious and cultural beliefs) are also necessary to determine a young person’s psychological maturity and competence to consent to medical treatment or involvement in research. If one was to use this comprehensive tool to assess competence for involvement in research, I would suggest many adults would not be considered competent!

The balance between protection and consultation of young people can be achieved by
ensuring the methodology addresses the ethical issues that could potentially prevent vulnerable groups from participating in research.

**Interviewing Colleagues**

Recruiting nurses as participants for this study has its own set of potential problems. In this study I recruited nurses through a large, state-wide organisation that has the responsibility for providing inpatient services to young people experiencing serious mental health problems requiring inpatient care. This may sound as though there is a large pool of potential participants. However, the hospital is a small city, and when the target group is nurses who have worked in a child and adolescent psychiatric inpatient unit, this limits the pool significantly. Indeed, I would be known to the majority of this pool of nurses through my work in various roles in CAMHS services in that State.

There are a number of reasons put forward to account for the limitations of what is called ‘the insider perspective’. Firstly there is a general tendency to take things for granted. This makes it more difficult for someone who is familiar with a particular environment to question aspects that appear self-evident. Secondly, it is asserted that an insider lacks the distance that is necessary to maintain a balanced and objective view of that environment. Thirdly, as a group member, the insider is discouraged from asking questions or questioning accepted norms. And finally, it is suggested that the insider may be reluctant to ask sensitive questions whereas an outsider may be less inhibited about asking questions which explore deeper meanings (Bonner & Tolhurst, 2002).

These arguments have been countered by black and feminist writers who assert that traditional research methods, which privilege the perspective of the stranger or
outsider, are actually privileging the voice of the majority in preference to that of the minority. The insider/outsider discourse does not take in to account that all observers come to that observation or interaction with their own experience, knowledge and cultural understandings.

**Method**

In this study I use phenomenology as a method of inquiry into the meaning of hospitalisation as experienced by young people with first episode psychosis. The primary concern of phenomenology is the nature and meaning of human experience as it is lived. It focuses not on an objective entity, but on phenomena as it is experienced and lived. The aims of a phenomenological study are very different from those of natural science in that it does not aim to identify causal factors, explanations or categorisations, but to explore a deeper understanding of a phenomenon and how it is connected to human existence rather than an absolute truth. In the present study a phenomenological method of enquiry enables the exploration of ‘hospitalisation’ to move beyond the traditional technological statements identified by natural sciences, and to be open to and inclusive of what it is that is being experienced.

As detailed in the previous chapter, the debate about the diagnostic categorisation of psychotic illnesses and the definition of schizophrenia has intensified over the last few decades, resulting in numerous explanations or conceptualisations about the causal nature of psychosis. The domination of the unitary disease model conceptualisation has significantly influenced research, limiting alternative research approaches that may focus on the experience of the young person with first episode psychosis. In particular, the phenomenon of hospitalisation for young people with first episode psychosis is an area that has received little focus despite the recognition
of the negative effects of hospitalisation and the call to provide treatment in the least restrictive environment.

Just as Heidegger identifies the way in which modern science as theory cannot fully explore the essence of a phenomenon because human nature constantly presents itself in different ways (discussed in Chapter Three), Gadamer also spells out the problem embedded in the process of using traditional scientific method to explore issues in the human sciences.

The problem that the human sciences present to thought is one that has not properly grasped the nature of human sciences if one measures them by the yardstick of an increasing knowledge of regularity. The experience of the socio-historical world cannot be raised to a science by the inductive procedure of the natural sciences. ... Historical research does not endeavour to grasp the concrete phenomenon as an instance of a general rule. (Gadamer, 2004, p. 4)

The present study is predicated on the assumption that a deeper understanding of the phenomenon of hospitalisation in first episode psychosis can be gained from exploring the experience of those who have been hospitalised or are closely involved in that experience. However, there may be times when other factors impact on the ability of phenomenological research to accurately capture this understanding. For example, when participants are unable or reluctant to communicate their experience to others for whatever reason, this limits the extent to which a phenomenological process can uncover deeper understandings. For instance, in the early stages of the present study, it was suggested by some clinicians that young people who had recently been hospitalised following the experience of psychosis would be unable to accurately describe the experience of hospitalisation because they would be unable to
differentiate the experience of hospitalisation from that of psychosis. From the outset of the study there were questions as to how accurately the young participants would be able to communicate their experience.

In applying a phenomenological research methodology to this study, I work from the assumption that in most cases the participants are able to communicate their experience and that they are the expert in their own lives and experience (White, 2000). The contribution of family members and nurses, who are both witnesses to and active participants in the hospitalisation, seeks to enrich the understanding of the phenomenon of hospitalisation by exploring it from different perspectives.

**Recognising Prejudices and Assumptions**

Every researcher brings with them prior understandings of the phenomenon that is being explored. While it is not possible to bracket these assumptions or set them aside, an important aspect of the hermeneutic process is to bring these prejudices or preconceptions to awareness throughout the research process. As has been previously stated, some of these prejudices may play a positive role, but some may need to be challenged in order for them not to influence the data collection or interpretation.

My past experience in mental health nursing, my studies in the area of child and adolescent mental health and my familiarity with current clinical practice have all contributed to the prejudices and assumptions that I bring to this research. I have worked in a variety of inpatient and community mental health settings and have experience in providing nursing care for young people experiencing first episode psychosis and their families in both arenas. However, I do not have personal experience of psychotic illness and I have no experience of hospitalisation since my early childhood.
When I commenced this study my understanding of a psychotic episode during adolescence was that it constituted a major mental illness that impacted on all aspects of the young person’s life. I believed that treatment involved the use of strong psychotropic medication, the side effects of which often compounded the impact of the illness itself. I witnessed the stigma of mental illness that exists in the community that marginalises young people who have experienced psychosis. I also witnessed that stigma embedded in some of the clinical practices in mental health settings. I heard young people and family members talk about the impact this stigma had on their experience of illness and recovery both in the community and in inpatient settings. My sense was that the family also experienced the stigma of mental illness and mothers in particular endured clinical practices that evidenced the influence of the psychoanalytic model of mental illness and the theory of the schizophrenogenic mother.

In my clinical practice, young people who had experienced psychosis told me about the impact their illness had on their peer relationships, particularly when following hospitalisation. They spoke of their fear of being different, of their loneliness and the difficulties in maintaining friendships.

I believed that the experience of psychosis was frightening at any age, but even more so during adolescence when there are so many changes taking place and relationships with peers are so important. I observed that accessing help during the first episode of psychosis was often difficult and navigating the mental health system was very complex.

I believed that the young person’s psychotic experience was equally frightening for family members and that the involvement of the family in care was paramount to a
positive outcome. This belief was not shared by all clinicians and led me to challenge practices that separated or distanced young people from their families.

From my clinical experience I thought that young people who experienced first episode psychosis required hospitalisation to stabilise their mental state and commence medication, and this hospitalisation was often a negative and sometimes traumatising experience. In the last five years I saw that these young people were spending shorter periods in hospital and had less opportunity to develop positive therapeutic relationships with nursing staff in inpatient units. There seemed to be a general acceptance by nursing staff that the hospital experience for someone with first episode psychosis would be difficult and the explanation given to this was that the young people were reacting to the experience of the psychosis itself.

One of the core tenets of my work was that any client, including those with first episode psychosis, should be treated respectfully and that the development of a strong therapeutic relationship was the basis for any intervention and should be reflected in all policies and procedures. I did not favour behaviourally based treatment approaches or psychotherapeutic approaches that situated the client or family in a deficit model. Respectful interactions were important even when the young person was acutely unwell, emotions were running high or the young person’s behaviour was putting themselves or others at risk. It is my contention that through the relationship with the young person and family, the nurse demonstrated respect, acceptance and care.

Throughout the process of the study my preconceptions and prejudices were challenged through questioning and discussions with my supervisors, one of whom did not have a mental health nursing background. This enabled her to ask questions
from a different space, challenging preconceptions that I had already uncovered as well as some that I had not. Rather than trying to eliminate my unstated understanding of this subject, throughout the research process I have tried to articulate and develop them as a resource in the process of interpretation.

**Selection of Participants for the Study**

One of the key assumptions in phenomenological research is that knowledge of a phenomenon can be gained from those who experience it (Munhall, 1989). In order to gain access to the phenomenon of hospitalisation as experienced by young people following the first diagnosis of psychosis, I explored the issue from a number of textual locations. This included interviews with those who had direct knowledge of the experience of hospitalisation following the first episode of psychotic illness, and those who had had witnessed that experience. Initially I conducted open-ended, unstructured interviews with a purposive sample of young people aged between 15 and 20 years who have experienced their first episode of psychosis and have been hospitalised following that diagnosis. The purpose of these interviews was to explore the descriptions of *what is there* that they have experienced, particularly the situation, temporality, concerns and common meanings.

Rather than trying to obtain a representative sample of age, gender or socio-economic status, young people who had experienced hospitalisation were invited to take part in the study to share that experience in a research context. The following criteria were used:

1. That they had been admitted to a hospital for the assessment and treatment of a psychotic illness.
2. That they were stabilised on medication and in the recovery phase of the
A phenomenological study of hospitalisation for young people with first episode psychosis

Chapter 4: Methodology

acute episode.

3. That they were living in the community.

4. That they were being supported by mental health services in the community.

5. That they were able to communicate in English without difficulty.

6. That they had given written consent to participate in the study (and their guardian had given consent if they were under 18 years of age) after an explanation of the study and their involvement in it.

These invitations were issued through two third parties, being the Mood Disorders Association (now known as Mental Illness Fellowship), a national support service for people suffering from mental illness and their carers, and the major public children’s hospital in the State that held responsibility for providing inpatient care for young people with mental illness and partial responsibility for secondary community mental health services. I felt that approaching young people through third parties that had strong commitments to the care of those with mental illness provided the first level of protection for the young people and, in the case of the participants sought through the mental health service, the potential for the clinician involved to reinforce the voluntary nature of involvement in the study. Those participants sourced through the Mood Disorders Association were given my contact details, and the names of potential participants identified through the mental health service were provided to me through their clinicians.

I then telephoned potential participants, gave them a brief outline of the study, and then made an appointment to meet with them, and their guardian if they were under 18 years of age, in order to discuss the study in more detail. I discussed the study,
provided them with an information sheet explaining their rights if they were to be involved in the study and provided them with an opportunity to discuss this with other family or friends. A follow up telephone call was then made to finalise involvement in the study.

I asked the young people who agreed to participate to name a family member or significant other who was close during the period of hospitalisation who would be prepared to be interviewed about their witnessing of the young person’s hospitalisation. The young participants and the family member or significant other had the right to decline this request. The purpose of interviewing family members was to provide added richness to the account of hospitalisation. The family members for three young participants did decline to participate and one young participant did not wish their family members to be involved. A similar number of nurses working in a mental health inpatient unit were interviewed about their witnessing of young people’s experience of hospitalisation. In these interviews I asked the nurses to move beyond the observation, to attest to, be beside, to stand alongside of the young people rather than describing the processes involved in their care. This exploration of the witness of family members and nurses provides the opportunity to develop a comprehensive representation of the phenomenon of hospitalisation as experienced by young people with first episode psychosis.

The concept of witnessing moves beyond recognition. It involves taking an ethical stand, bearing witness not only to that which can be seen, but also to that which cannot be seen. The granting of recognition reinforces the dynamics of power by the objectification of the other and the othering of difference, thereby denying those that are marginalised in society a voice. Witnessing addresses the subjectivity of the other
and provides space from which marginalised groups can speak (Oliver, 2004).

The eventual sample of the study included eight young people (four young men and four young women), four family members (all women) and five nurses (three women and two men). All of the nurses were registered mental health nurses and had completed a university degree and a post graduate diploma in mental health nursing. Their years of experience in child and adolescent mental health nursing ranged from two years to fourteen years.

All participants were given a pseudonym that was used in the transcription of interviews and for this report. Some details of the young people's histories have been changed to protect their confidentiality.

The main process for obtaining data in qualitative research is the interview process using a semistructured interview agenda (Packer, 2011). In this process there is a general plan for the topic but the interview does not follow a particular order nor are questions asked in a specific way. The relationship between the interviewee and the researcher is seen as a crucial part of constructing the text. The researcher takes a stand, not of neutrality, but of curiosity and flexibility, using the resources of everyday conversation to help the participant to put into words what they have experienced and the meaning of that experience. The text, or what is said, is reflective of but does not constitute meaning. The interaction between the participant and researcher is acknowledged and the researcher uses everyday conversation to address the power differential between themselves and the participant in an attempt to render themselves invisible, thereby allowing the participant’s experience and the meaning they have given to it to dominate (Packer, 2011).

The interviews that created the data analysed in this study generally took the form of
a narrative in two ways. First, the interview process in itself is seen as a narrative in that it stands by itself and has a beginning and an end. Second, the interviews attempt to tell a story about the participants’ experience of hospitalisation, whether that was direct experience or the witnessing of that experience. These accounts did not necessarily follow chronological order in telling what happened, but reflected the significance of events in a broader context. “In sum, narrative illuminates temporality and humans as temporal beings” (Prince 1987, cited in Packer, 2011, p. 103).

**Interviews with Young People and Family Members**

Interviews were conducted at a place and a time that was convenient for both the participant and the researcher. Some young people and family members chose to be interviewed at home and some in a private room at the mental health clinic that was familiar to them. These interviews were taped with a digital recorder and transcribed for detailed analysis. Each participant was given a hard copy of their interview and provided with an opportunity to make changes. Only one participant chose to provide additional information.

The potential for causing additional distress to young people by having them re-tell their distressing experiences during the interviews was balanced by the therapeutic potential for validation by bearing witness to that experience. Going through a psychotic episode is a frightening and often isolating experience and young people have few opportunities to talk about these experiences. While many of the young people cried while recalling the distressing aspects of their experience, they also found it helpful to tell their story and try and make meaning of what was a confusing and unfamiliar experience. Once young people have been discharged they have limited contact with other young people who have experienced psychosis, so the
interviews provided the young people with an opportunity to talk about their thoughts and feelings about their experience of hospitalisation and have these validated.

As discussed earlier in this chapter, different beliefs and perceptions about the nature of childhood have lead to different approaches to seeking young people’s views. Similarly, different beliefs and perceptions about the nature of mental illness have influenced the ways in which researchers have sought to involve young people experiencing mental illness in research. Identifying young people who have experienced mental illness as vulnerable or less competent to be involved in research reflects a tendency to de-value young people’s contribution to the expansion of knowledge (Morrow & Richards, 1996). By addressing the ethical issues that could potentially prevent vulnerable groups from participating in research, a balance between protection and consultation of young people can be achieved.

The young people, parents and siblings who agreed to participate in the study all expressed the value of telling their story despite the emotional impact this incurs. Most of the young people, parents and siblings who participated expressed this emotional impact through tears before the interview even started. Amy, who was 17 years of age when she first experienced psychosis, cried for a few minutes before the interview started, but when offered to defer or even cancel the interview, she said:

   *No. No. It was really hard, it was really hard, but I want to say it, I want to tell it [my story]. (Amy, p. 1)*

Pam, whose daughter first experienced psychosis at 16 years of age, said that even though it was difficult to talk about a time that had been so difficult for the whole family, she wanted to persist because:
...the more they [health professionals] understand about this the more they can help us. (Pam, p. 1)

Providing an environment within the interviews that was empathetic, emotionally containing and flexible, enabled all young people, parents and siblings to be more beyond their initial expressions of overwhelming emotion to tell their story of the experience of or witnessing of hospitalisation.

**Interviews with Nurses**

Interviews with nurses were conducted in a closed office at their place of work ensuring privacy. The nurses were first asked to provide information about their nursing qualifications and their years of experience in child and adolescent mental health nursing. This was followed by more specific questions about their witnessing of young people’s experience of hospitalisation. They were asked to recall their involvement with one particular young person who had been admitted with first episode psychosis and to talk about their witnessing of that young person’s experience, then make general comments about the experience of hospitalisation for young people with first episode psychosis. The nurses were asked to reflect on how the young people experienced the nursing procedures and Ward routines. These interviews were also recorded and transcribed, and a hard copy of the interview was provided to each nurse.

**Description of Participants**

**Young people:**

1. Max was 18 years old at the time of our interviews. He had been diagnosed with bipolar disorder approximately one year prior to the interviews, although he believes that he had been unwell for at least six months before that. He
A phenomenological study of hospitalisation for young people with first episode psychosis

was detained under the *Mental Health Act* and hospitalised for five weeks following a period of approximately a month of escalating mania. He has been stabilised on Sodium Valproate and Olanzapine. He lives in a new housing trust home with his mother and his older brother who attends University. He is currently doing an acting course at TAFE, which requires him to attend five days a week, with additional time for performances.

2. Sara was 20 years old at the time of our interviews. She experienced her first episode of psychosis eighteen months prior and had subsequently been diagnosed with bipolar disorder. Her first admission to hospital had initially been voluntary, however escalating fear drove her to leave the Emergency Department and ring her Aunt who brought her back to the hospital where she was detained. Sara lives independently and is studying at University.

3. Amy was 18 years old at the time of our interview. She was diagnosed with schizophrenia three months prior to the interview after being arrested by Police and subsequently detained under the *Mental Health Act* and hospitalised for three weeks. She had been trialled on a number of antipsychotic medications unsuccessfully, and was currently prescribed Olanzapine\(^9\). She lives with her parents and two younger siblings and is not engaged in any work or educational program. Her mental health worker was recommending re-admission to hospital at the time of the interview which she was strongly resisting.

4. Joe was 17 years old at the time of the interviews and he had been taken to hospital by his mother seven months earlier after experiencing hallucinations

\(^9\) See glossary for further information.
relating to the use of marijuana. He stayed in hospital for four and a half weeks. He has been stabilised on Respiridone\textsuperscript{10} and meets with his mental health worker every two weeks. He lives with his mother and visits his father on a regular basis. He has plans to go back to work in the factory where he was working prior to the onset of his illness.

5. Penny was 17 years old at the time of the interviews. She was diagnosed with psychosis during hospitalisation that followed a three month period of escalating disorganised and erratic behaviour. Her first hospitalisation lasted for three weeks. She has subsequently been diagnosed with a degenerative neurological disorder. She lives with her parents and two siblings and attends a private school.

6. David was 16 at the time of the interviews. He was taken to hospital by his father at the age of fifteen after experiencing hallucinations after using marijuana. He was hospitalised for five weeks. He had previously been diagnosed with Attention Deficit Hyperactivity Disorder\textsuperscript{11}. He had been trialled on a number of antipsychotic medications and was currently prescribed Olanzepine. He lives with his parents and older sibling and attends a day program for young people with mental health problems two days a week.

7. Chloe was 16 years old at the time of the interview. She was hospitalised 12 months prior to the interview after she was involved in a car accident. She was medically assessed in the Emergency Department prior to being transferred to the psychiatric ward. She has then diagnosed with

\textsuperscript{10} See glossary for further information.
\textsuperscript{11} See glossary
schizophrenia and was prescribed Respiridone. She has had a number of admissions since and there was evidence of neuroleptic syndrome\textsuperscript{12} during the interview. She lives with her mother and attends a day program for young people with mental health problems one day a week.

8. Dan was 17 years old at the time of the interview. He had been hospitalised five months prior to the interview for a period of six weeks after his behaviour became increasingly disorganised. He was diagnosed with schizoaffective disorder. During his admission he was restrained and placed in seclusion on a number of occasions and was transferred to a high security adult psychiatric facility for a period of five days. He lives with his father and older sibling and is not engaged in any work or educational program.

No biographical detail was collected for the family members and only data relating to qualifications and years of child and adolescent mental health nursing experience was collected for the nurses. This data is summarised below.

\textsuperscript{12} See glossary
Table 4.1: Background of Nurses

<table>
<thead>
<tr>
<th>No.</th>
<th>Pseudonym</th>
<th>Nursing Qualification</th>
<th>Years of CAMH Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Anne</td>
<td>B.Nsg., Grad.Dip. MH Nsg</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>George</td>
<td>B.Nsg., Grad.Dip. MH Nsg</td>
<td>14</td>
</tr>
<tr>
<td>3</td>
<td>Nicola</td>
<td>B.Nsg., Grad.Dip. MH Nsg</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>Patrick</td>
<td>B.Nsg., Grad.Dip. MH Nsg, M.Nsg</td>
<td>10</td>
</tr>
<tr>
<td>5</td>
<td>Danny</td>
<td>B.Nsg., Grad.Dip. MH Nsg</td>
<td>8</td>
</tr>
</tbody>
</table>

Analysis of Texts

In addition to analysing the interview texts, I reviewed the policies and procedures that currently guide practice in this area and the Early Psychosis Intervention and Prevention (EPIP) discourses that are dominant within current literature because they form part of the nurses’ world. This review of policies and procedures was undertaken not as an in depth analysis of words and concepts, but to understand the principles guiding nursing care in a child and adolescent mental health inpatient unit. I conducted an analysis both across participant descriptions and between the different textual locations, circling the phenomenon, to discover meaningful patterns and concerns regarding the phenomenon of hospitalisation as experienced by young people with first episode psychosis.

Methods of Data Management, Analysis and Interpretation

In this study, data management involved having transcripts made of all interviews. As the participants were at times distressed or were using terminology unfamiliar to the transcriber, after receiving the transcripts I listened to each interview several times and reviewed each transcript to ensure that it was accurate. As transcription usually omits non-verbal features such as tone of voice, volume and gestures, I reviewed all transcripts to include these features as much as possible, particularly...
where there was non-verbal expression of emotion or a change in engagement. All texts were manually sorted into the three categories of participants and policy and procedure texts. Coloured markers were later used to identify information relating to specific groups of data.

The conceptual processes of data analysis are more difficult to describe in a concise manner. The interview process is intersubjective in nature, with the researcher and the participant interacting in both verbal and non-verbal ways. Capturing this interaction in a transcript in some way fixes what is said at a point in time. In reviewing the transcripts and adding the emphasis, expressions, silences and other non-verbal communication, I tried to capture a sense of that interaction in the interviews. As both interviewer and subsequent reader of the transcripts, I am actively interacting with and interpreting both the participant and the text. The text is not simply a message for decoding.

As text and reader thus merge into a single situation, the division between subject and object no longer applies, and it therefore follows that meaning is no longer an object to be identified, but is an effect to be experienced. (Iser, 1980, cited in Packer, 2011, p. 105)

The task in analysing the data is to construct a sense of the whole from partial views. The reader’s viewpoint changes or develops as the data is analysed (Packer, 2011). Iser refers to the analysis of texts as a dynamic process in which “...the reader’s understanding is continually prestructured and restructured” (Iser 1980, cited in Packer, 2011, p. 106).

In analysing the transcripts, I paid particular attention to the language used, the forms of expression as well as interaction around the pauses and expressions of emotion.
such as crying and laughing, changes in tone of voice and other non-verbal aspects of the interviews. The way in which participants tell their story was also analysed.

Being guided by the philosophical ideas, in particular, being-in-the-world, future possibilities, temporality and space, and witnessing, I read every word of each transcript to determine significance and question the ideas that seemed to be arising from the participant’s conversation. I continued this process concurrently with data collection and with each read of a transcript I gained greater insight into the hospitalisation experience. I began to see common ideas and patterns arising across the transcripts and between the perspectives of each group. From this I began to construct my interpretation into findings and present them in four key themes: Becoming Unwell, Limitations of Horizons, Witnessing: an ethics of concern, and Connectedness in Time and Space. Several sub-themes became subsumed under or into each of these key themes.

Through attention to the elements of narrative ... its blanks and negations, its tropes and plots and world hypotheses, this tacit understanding can be articulated, corrected, and communicated. (Packer, 2011, p. 119)

From individual words or phrases that occurred in the transcripts from the young people, family members and nurses, subthemes emerged. Using a mind mapping process (see Appendix 4), these subthemes led to four key themes which are documented in the findings chapters. In Chapter Five, Becoming Hospitalised, Heidegger’s concepts of thrownness, being-in-the-world and being-with-others became the philosophical ideas that Informed the analysis and resulted in three major subthemes: Becoming Unwell, Entering a Foreign Environment, and Learning What Helps.
In Chapter Six, Limitations of Horizons, the Heideggerian concepts that informed analysis in Chapter Five continue to have relevance as the impact of social and cultural beliefs towards mental illness on the participants’ being-in-the-world and future possibilities are explored. The major subthemes that were elucidated were: Labelling of Others, Being Confronted as the Other, Getting a Diagnosis, and Looking Towards the Future.

Oliver’s phenomenological concept of witnessing informed the analysis of the subthemes that arose and are documented in Chapter Seven, Witnessing: an ethics of concern. These subthemes were: Nursing Care, Observation, and Witnessing.

The subthemes that are documented in Chapter Eight, Connectedness in Time and Space, have been guided by Heidegger’s notion of temporality. The subthemes that reflected the complexities of temporal understandings of the time and space of hospitalisation were: The Hospital Space: a place of temporal refuge or safety?, Relational Space, and Whose Time is in Focus?

**Summary**

The vast literature regarding first episode psychosis, early intervention and treatment has done little to advance understanding of many aspects of the illness, in particular the experience of hospitalisation for young people with first episode psychosis. There have been calls in the literature for attention to turn to the subjective experience of those experiencing psychotic illness (Walton, 1995). The recognition that there is part of this experience that is not well understood indicates, in Heideggerian terms, that it has been concealed. The phenomenological approach provides a way to set aside the many theoretical explanations and suppositions, turning to the thing itself with what Heidegger calls ‘ceaseless questioning’.
In the next four chapters, the findings of this study in relation to the experience of hospitalisation will be presented. Chapter Five examines the impact of being thrown into the world of mental illness and the psychiatric ward. In Chapter Six, I investigate how this limitation of horizons is acknowledged and addressed within the hospitalisation by the young people, their family members and the nurses. In Chapter Seven that which matters to the young people and their family members, their everyday concerns regarding hospitalisation, are discussed and put side by side with an exploration of the concepts of observation and witnessing, and their place in mental health nursing. In Chapter Eight the interdependent concepts of time, space and temporality are explored in the context of safety and refuge for the ways they effect the experience of hospitalisation for all participants.
Chapter 5: Becoming Hospitalised

Introduction

In this, the first of four chapters in which the findings of this study are discussed, the young people who have experienced their first episode of psychosis and their families described the ways in which everything that is familiar fell away and they were thrown into a world that was foreign to them and not of their making. The young people’s experience of becoming unwell challenged their being-in-the-world and this influenced their experience of hospitalisation. As discussed in Chapter Four, Heidegger considers the human self and the world as one. We are shaped by the culture and historical environment in which we live, and at the same time are able to choose how we respond to our history and our culture. Each of us is thrown into a world that is not of our making, and how we respond to this world is influenced by our cultural and historical development and thinking. In sharing their experiences in this chapter, the young participants emphasise the impact this thrownness has not only on their experience of hospitalisation, but also on their understanding of who they are in the world and their concept of the future.

The impact of psychosis on prospective social, educational, occupational and relational attainments has been well documented. How we understand our relationship with the world and who we are in the world is driven by our everyday experience with things in the world and with other people. It is this experience and our goals and intentions that define us. The experience of an emerging psychosis, how this is identified and the treatment that is provided has a significant impact on the young participants’ sense of self and how they understand and relate to the world.
The effects of this unexpected and frightening illness also impacted on family members, challenging their understanding of themselves as parents and leaving them unsteady and anxious in their world. The nurses too experienced the unsteadiness and existential anxiety related to each new relationship.

**Becoming Unwell**

Many of the young people who participated in the study talked about the experience of becoming unwell that preceded the hospitalisation. They described the fear as their symptoms, as yet undiagnosed, escalated and the situations they found themselves in were beyond their control. The experience of becoming unwell with a psychotic illness was seen by all participants as a frightening journey into the unknown. The young people described both the changes in their thought processes and behaviour, and the response of others to their behaviour.

Amy described a slow deterioration in her mental health over a number of months prior to her hospitalisation, resulting in her becoming more withdrawn from her family and friends. She found it difficult to complete the tasks required of her at her workplace. She tearfully described the events that occurred after she had an argument with her father and had been sacked from her job:

...I just got lost in town while the pageant was on and saw a million different faces that all looked similar and different. So by the time I got there they’d go away and I thought it was them. And of course I was getting these messages at the same time and thought they were just around the corner or whatever. And I don’t know, by that time I had walked out of town into some suburban streets and knocked on somebody’s house. I don’t know who the hell they were but I thought my cousins were there. By the time I realised they had no idea who I
was or what I was doing there, so I walked down the street a bit further and saw the cops driving down so obviously I thought they’d called the cops on me. So I went off at the cops and then they had to arrest me and they got me on the ground. They pinned me down on the ground. And then they called an ambulance and they put me in the ambulance still tied up. ...And then I got to the hospital and they put me in a little room. (Amy, p. 1)

While the confusing images and thoughts she was experiencing aroused fear, Amy normalised these experiences and acted on the unusual experiences as if they were real.

For six of the eight young people who participated in the study, entry to hospital care was involuntary and involved detention under the Mental Health Act of [State]. This Act states that:

a medical practitioner or authorised health professional may make an order that a person receive treatment as an inpatient in a treatment centre (a *level 1 inpatient treatment order*) if it appears to the medical professional or authorised health professional, after examining the person, that-

(a) The person has a mental illness; and

(b) Because of the mental illness, the person requires treatment for the person’s own protection from harm (including harm involved in the continuation or deterioration of the person’s condition) or for the protection of others from harm; and

(c) There is no less restrictive means than an inpatient treatment order of ensuring appropriate treatment of the person’s illness. ([State]
In addition, if a Police Officer believes that a person has a mental illness and has caused or is at risk of causing harm to themselves or others, they can detain that person to a treatment centre for medical examination. Transport to the treatment centre usually involves the [State] Australian Ambulance Service unless there is significant concern about harm to others, in which case the Police will provide transport. It is most common that both Police and Ambulance services are present when a person is detained in a community setting for assessment or treatment. For Amy, with her confusion and fear resulting in dysregulated behaviour in a public space, the Police used significant force to subdue her prior to the Ambulance service transporting her to hospital.

For Joe the emergence of psychotic symptoms occurred relatively rapidly in the context of two years regular marijuana use. He found that the unreal experiences were overwhelming and relentless and changed his understanding of himself and his relationship with his world.

*I was actually smoking a few cones. I had too many cones at the time and I started hearing voices in my head. So by now I was banging my head on walls and getting real paranoid and that. And they (the cones) put me on trips and stuff like that and someone broke into my house. And yeah, it was real intense. It was like hitting my head against walls because of the voices and I had real headaches. And I told my Mum and that, and they put me in hospital. Yeah, it was really intense. Yeah, no it was, it really changed things; it changed me, like yeah.* (Joe, p. 1)

While Joe’s transfer to hospital was unremarkable in that he willingly went with his
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mother who he trusted, the intense experience of paranoia and uncontrollable thoughts was unbearable and made it impossible for him to continue with his work at a local factory or maintain his relationships with his friends.

From a phenomenological perspective, we are not simply located in the world, but we are bound to it by all the connections of activity, relationships, emotions and so on. Our everyday relationship with the world is what Heidegger calls ‘concern’, and this relationship is very practical – producing, constructing, enjoying – intimately connecting us to the world. It is in terms of this concern that ‘things’ receive their significance as they are incorporated into our world. Space gets organised into a system of places and time is organised in terms of our practical concern – a time to get up, a time to eat, a time to study and so on (Macquarrie, 1968, p. 16). The routine everyday activities that we engage in mask the fundamental problematic nature of our being-in-the-world, instead appearing as commonplace and ordinary, while at the same time reflecting the essence of our relationship with the world. These ordinary ways of being-in-the-world include “...having to do with something, making use of something, giving up something and letting it go, undertaking, accomplishing, evincing, interrogating, convincing, discussing, determining and knowing something. This last way of being-in-the-world is especially noteworthy” (Steiner, 1978, p. 83).

When this relationship with the world is disrupted or changes in unexpected ways, our routine and conventional ways of being-in-the-world are challenged. Joe’s being-in-the-world had altered dramatically. He was no longer able to do the things that had previously occupied him. He was very proud of his employment in a local factory as it demonstrated his commitment to support himself financially. His relationship with the world through his work had been disrupted and he had been thrown into a world where he could no longer control his thoughts and environment. While he was still
recovering from his first episode of psychosis at the time of interview, his everyday relationship with the world was becoming more familiar despite some residual symptoms and side effects of medication. He remained focussed on returning to work as that was a significant aspect of his being-in-the-world.

In the normal course of life people rely on their sensory experiences to interpret their relationship with the world. These sensory experiences are not challenged but are accepted as truth, or as Heidegger would say, they are taken-for-granted. It is only when something goes wrong with the taken-for-granted that we pause to reflect on what is happening and think about whether things are as they seem. Until the taken-for-granted breaks down, we do not consciously examine it and things are assumed to be consequential and logical. The unusual sensory experiences associated with psychosis were initially not challenged by the young people, but incorporated into their understanding of themselves and their relationship with the world.

Max believed he was unwell for approximately six months prior to his hospitalisation, displaying manic, uncontrolled and high risk behaviours. The deterioration in his mental state was noted first at school where his unpredictable and risky behaviours were assumed to be associated with drug use. He was detained under the Mental Health Act by a psychiatrist at home when his mother Sue requested assistance from a local mental health service. Prior to hospitalisation Max did not challenge his sensory experiences but acted in a non-reflective way, in spite of his behaviour seeming to others to be unusual.

And then I told pretty much everyone in high school that I was going to be performing with my band in [Name] Square and about 15 people turned up and I didn’t have a band ... and they were like, ‘You’re crazy! You need some
help!’ I said no I don’t, I’m fine ’cause I really did think I was fine. And I’m like, ‘Well I’ll break dance for you... ’. (Max, p. 3)

In describing the process of his detention after several weeks of escalating manic activity, Max depicted being pushed from a world in which his thoughts, behaviour and judgement may have seemed unusual to others, into the unknown. Max describes being unsure and confused, with things moving too fast for him, despite his manic state of mind.

And yeah, a psychiatrist came... I was so pissed off and I said ‘Mum, what are you doing? You brought a psychiatrist here! I’m fine!’ [The psychiatrist] said ‘I think you’ve got bi-polar and I’m going to issue an order for your detention.’ And I’m like “what!” I was kind of shocked to begin with but then I said, ‘Nuh, I’m not going!’ Then she’s like, ‘You have to go otherwise we will forcibly make you go.’ So then they forcibly made me go which was a bit of a bummer. ... I grabbed my book and I was only wearing shorts and a T-shirt. I didn’t have any shoes on. ... When I got in the ambulance I was a bit shaky, like maybe you’re going a bit fast for me. (Max, p. 4)

The usual way of Being-in-the-world for the young people who were experiencing psychosis was being challenged. Max had new skills to entertain people and was puzzled that his friends did not appreciate these. Dan received messages from God and could tell when others were possessed. Joe was frightened by the voices in his head and tried to stop them by banging his head. Chloe was experiencing abdominal pain after an accident and was confused when she was forced to stay in hospital without her mother. All of the young people who participated in the study talked about their thoughts and behaviour prior to their admission with clarity and at the
time did not doubt their own judgement.

Both young people and family members described situations prior to hospitalisation in which their understanding of their relationship with the world and their own being is challenged by anxiety and a sense of what Heidegger calls “not-at-home” or uncanniness. Heidegger is not using a psychological or physiological definition of anxiety, but refers to its latent existence in the relationship a person has as they sit alongside the ‘world’. When the familiarity of the everyday falls away, one is said to be anxious. “Only because Dasein is anxious in the very depths of its being, does it become possible for anxiety to be elicited physiologically” (Heidegger, 1962, p. 234). When the practical everyday activities and routines with which we are familiar run smoothly, we recognise our relationship in the world and can see ourselves as separate from the world. When we do not recognise what Heidegger calls the ready-to-hand we become anxious and unsteady. For all of the young people involved in the study, even their familiar environment of home and school or work had become uncanny and the environment into which they had been thrown created an existential anxiety that made them unsteady.

Dan identified the stress relating to his first job as a kitchen hand in a restaurant and his occasional marijuana use to manage this stress as precipitators to his increasingly disorganised behaviour and visual and auditory hallucinations. Dan described his experience prior to coming into hospital as a ‘journey’ that you move through despite not knowing or being confused about what was happening. The only thing that was familiar to him in the process of admission was his father’s attempts to keep him safe, a recurring theme as he related the story of his first hospitalisation.

... then I started to have visions and voices like, and it wasn’t harming me or
anything like that. It was like an experience spiritually. ... We were listening to the radio, like the football station and it’s like they were talking to me while we were driving. ... It was hard to make sense of. ... But when you try to journey through it you really don’t care at all, what’s going on or anything. And of course the people around you do care because they’re trying to get you better. So you just put your seatbelt on and take journey out and that’s what happens.

(Dan, p. 2)

Dan could no longer recognise what was ready-to-hand but he tried to comprehend these new visions and voices through his religious beliefs, believing he was receiving messages from God. Despite the confusion and inability to understand his new relationship with the world, he found it reassuring to rely on his spirituality through which to comprehend his current circumstances. It was during his hospitalisation when antipsychotic medication had started to reduce the positive symptoms of psychosis that this reassurance was stripped away finally, once again leaving him anxious and unsteady.

The family members involved in the study also talked about the alteration to their Being-in-the-world as parents and siblings. They described the distress and fear they experienced in the period leading up to the hospitalisation. Understanding what was happening for the young person and witnessing their fear and agitation challenged the family members’ relationship to their world, their view of themselves and their family. Sue, whose son’s mental state had been deteriorating over a period of six months, had not been aware of the high risk behaviours that he had been engaging in as they were taking place outside the home. She was requested to come to the school to discuss their concerns about her son’s agitated behaviour with the school believing that this was related to drug use. Sue was aware that she had not attended parent
teacher meetings for some time and felt that her role as parent was somehow now under scrutiny.

Everything was fine with Year 11, but in Year 12 there were notes coming home, like he hasn’t done this, he hasn’t done that, which was unusual. They said that he had been rude to staff etc, etc, which was very unlike him ... he’d always been really liked. So I went up to the school. I hadn’t followed up on going to see the teacher, that parent teacher stuff, so I was a bit anxious about going to the school. (Sue, p. 1)

After hearing the extent of the school’s concerns and consulting with a local mental health service Sue described feeling powerless and forced into taking action that would limit her son’s freedom.

I’d sort of been warned about what could happen that day [he was detained], but the reality is ... you can get warned for something, but when it actually happens it’s really upsetting. ... I could hear the psychiatrist talking to him, and I could hear him getting more and more agitated, and I thought, okay, this isn’t going very well. ... It was very upsetting. Yeah, it’s quite numbing actually. It didn’t seem real. I’m signing detention papers you know, because he was actually under 18 at the time. (Sue, p. 2)

Sue described her fear that her son would feel betrayed if he had known she was signing his detention papers, and this reflected her son’s outrage at a psychiatrist being invited into the family home. After he had been taken to hospital by ambulance, Sue described feeling overwhelmed by the decisions she had to make and the silence of being alone with those decisions.

So yeah, they took my son, and yeah, it was when they were gone, it was like
the place is too quiet. I probably sat down and cried for ages. But I had to get myself out of the house. It was just, even though it had happened, it still didn’t seem quite real. (Sue, p. 3)

It is through our everyday experience with things in the world, with other people, in our goals and intentions, that we are defined. According to Heidegger (1962), we are thrown into the world, dealing with what it receives from the past. We are already part of the world as we are. The situations into which we are thrown have future possibilities, an ability-to-be, but also limitations. We are pre-occupied with the world in the present, dealing with its concerns that are ready-to-hand and limited by the collective culture of the world that Heidegger calls the Them-world. We are shaped by historical and cultural understandings, but have the ability to make choices within that. Sue found herself thrown into the world of mental illness of which she had little experience, and community understandings of having police and ambulance assistance at the home were crowding in on her while she was focussing on making the best decision for her son.

I didn’t know whether he was going to be stroppy or stuff, and I thought well I want this to go down quietly and not have the cops involved, because our street at the time, you would have every single neighbour out in the street, the fact that an ambulance pulled up! Yeah, I don’t know, the police had a four minute response time to our street! (Sue, p. 3)

Pam’s daughter Penny experienced her first episode of psychosis at the age of sixteen years. After a three month period of escalating behaviour, a deterioration in her academic performance and increasingly bizarre behaviour, Penny was detained to hospital under the *Mental Health Act* for assessment. Witnessing Penny’s distress
was very frightening for Pam and her family. She described the fear of being thrown into a world that was unfamiliar and frightening, and the collective culture of the Them-world regarding the responsibilities of parents influenced her perceptions of what was happening.

_When something happened I was so worried. I was asked to come to the school because they were worried about her. I was so scared. I didn’t know what to do so I asked my doctor and he said to take her to hospital. ...I didn’t know what was happening to her. I thought I had done something wrong, that I had not looked after her properly. ...I felt so guilty about my care for her – not enough care._ (Pam, p. 1)

Thrownness is being in the world outside of one’s control, not of one’s choosing. We are all born into a world that is not of our making and we spend our life making sense of our relationship with this world. Pam’s world contains things for which she is not responsible and did not choose. Her world now contains things of which she has no knowledge or experience.

_I asked her to go to the doctor and she said no, she didn’t want to go to the doctor. Then in the night we woke and she was screaming at the floor. My husband asked her why are you screaming at the floor? I helped her up and took her to her room and just said ‘Sleep’. And she laughed, she laughed too much. She was watching TV in her room but there was nothing on it to laugh at. And then she ran away. ...it was winter. I was very scared._ (Pam, p. 2)

While she is thrown into a world that is unfamiliar and frightening, Pam still has room to manoeuvre, in which to make choices and take responsibility. However there are constraints to these possibilities, including the context in which these young
people and families find themselves, the limitations and access to knowledges and skills. The way in which young people and family members are thrown or project themselves forward into other possibilities is discussed in Chapter Six.

The traumatic experience of becoming unwell clearly had an impact on the young people’s experience of hospitalisation, and in particular during admission to hospital. They described their fear and distrust as they were forcibly thrust into the unfamiliar and frightening environment of psychiatric ward and the suspicion that clouded all their interactions, particularly with nursing staff with whom they had most contact. The young people and family members were able to describe the experience of becoming unwell and connect with the accompanying emotions, distressing as they were, and separate that from their experience once admitted.

Despite the impact that the pre-hospital experience has on young people’s experience of hospitalisation, only one of the nurses commented on the distress the young person and family had experienced prior to admission to the Ward. All the other nurses who participated in the study carefully described the symptoms that they were witnessing and the nursing care they provided in response to those symptoms. They emphasised the history of symptomatology, the disconnection from school or deteriorating grades, and the level of agitation on admission. Anne, a Registered Mental Health Nurse with three years’ experience, described her first encounter with a young woman in an inpatient unit.

*I can think of one sixteen year old girl and she presented with a history of becoming quite isolated, marks going down at school, easily distracted, obvious responding to voices, that sort of thing. She had about a six month history of this and she was very, very unwell when she was finally admitted. ...*
She appeared very detached from reality. She had a very short attention span.

(Anne, p. 2)

Anne was clearly familiar with the diagnostic descriptors associated with psychosis, however there was no mention of the impact the experiences prior to hospitalisation had on the young woman or her family.

Conversely, Patrick, a Registered Mental Health Nurse with ten years experience, identified the impact of the trauma experienced prior to hospitalisation had not only on the young person, but also on the parents and siblings.

I think the hardest thing was, the poor boy was so overwhelmed by, and traumatised by his symptoms. But I think more importantly, looking at his mum and dad and his younger brother looking at the sudden changes in him, was probably the most frightening thing. And frightening in the sense that he felt no control over what was happening in his life, and it was quite heart wrenching watching him cry and be distressed... (Patrick, p. 1)

For some nurses it was the level of agitation on admission that guided their nursing response. George, a Registered Mental Health Nurse with 14 years experience, described the reaction of staff to high levels of agitation or physical danger when a young person with first episode psychosis is admitted.

It can be messy if there’s high levels of anxiety in the patient or we perceive some high anxiety or some amount of danger in the patient. Yeah, now that I’m thinking about it, if the patient isn’t terribly, terribly distressed and it doesn’t look like they’re going to be a threat to themselves, but especially to us, we’re a lot more relaxed and we take time. When the patient looks big, male, angry and wanting to fight, that’s when we all rush around, tripping over ourselves to
George speaks of anxiety here as a marker of psychological distress rather than the Heideggarian construct of anxiety, a state in which “everyday familiarity collapses” (Heidegger, 1962, p. 233). One is anxious not about a particular thing but about one’s Being-in-the-world, one’s lack of familiarity with the world. George’s initial focus on levels of anxiety and physical danger is underpinned by his aim to use his relationship with the young person and their family to develop an atmosphere of safety and security. The use of relationship is a key tool in mental health nursing and will be discussed further in Chapter Eight.

George’s comment also adduces the existential anxiety that the young people, their families and the nurses’ experience around this first encounter in the ward. Both George and Patrick have pointed to the source of their existential anxiety, namely the depth of suffering and distress that these young people and their families are experiencing, and the impact this has on them as nurses. Being open to the distress of others exposes these nurses to their own thrownness, leaving them being what

13 p.r.n. or pro re nata is the Latin for ‘in the circumstances’ or ‘as the circumstance arises’. It refers to the dosage of prescribed medication that is not scheduled, instead administration is left to the nurse’s, caregiver or patient’s prerogative, not exceeding a daily dose.
Heidegger calls uncanny or not-being-at-home. The unsteadiness which results from this existential anxiety is experienced by all parties in this new relationship and occurs in an environment which is familiar to the nurses (although theirs is with a person with whom they are unfamiliar) but foreign and frightening to the young people and families.

**Entering a Foreign Environment**

For the young people in the study, entering a psychiatric ward for the first time was an experience braided through with fear, confusion and lack of control. With their relationship with the world being challenged by the frightening symptoms of psychosis and the nature of their detention into hospital care, they were then thrown into the unfamiliar environment of a psychiatric ward. Max, despite his manic state, experienced the fear of the unknown and adjusted his perception of his current predicament to give himself more time to understand what was happening.

*I got to the hospital and walked in. I got really scared because there was this guy that I thought was crazy and he was staring at me and I was like, ‘Oh God, there are crazy people here! ... they led me through all everything. They weren’t restraining me and everything. But I was walking through and I was noticing all the doors and I thought wow, this was really cool, like how they’ve got security cameras and shit. Yeah, I went through the doors and everything and I got a little tour around the place and I treated it like a real estate inspection [laughter]. ... I was pretending I had complete control over the situation [laughter].* (Max, p. 4)

In determining how he was to understand his place in his current environment, Max asked questions about privacy and freedoms that would be allocated to him, and then
compared that to his normal experience of being-in-the-world. He found enough that was familiar and positive to alleviate his anxiety:

I asked for a private room and they said no. And I’m like, ‘I can lock the doors behind me, and they’re like, ‘No you can’t’ and that was annoying. ... I couldn’t go outside, but it was great inside. Well, the actual set up was. Okay, free food, stuff that’s cooked for me, don’t have to do dishes – it was like a holiday resort compared to my place. (Max, p. 4)

For Dan, who thought he was coming to the hospital with his father to visit someone, it was the strength of his relationship with his father that overrode the fear invoked by the frightening psychotic symptoms and the unfamiliar environment.

I realised it was for me to be staying in the hospital and I didn’t like that so I started to walk off. And then Dad was saying, ‘He’ll get lost! He’ll get lost!’ So I turned around because I didn’t want to take the chance. But it was like a huge thing, it wasn’t something simple where a kid gets lost, like a kid walks off and the parent was saying to come back. It was something more than that, like, yeah. And all the voices, like the people who were talking to me were really intense and loud and that. (Dan, p. 1)

The primacy of this relationship to his understanding of his being-in-the-world was clearly stated when he said:

My brother’s got my Mum’s genes, but I’ve got my Dad’s genes, so he’s really right to me! (Dan, p. 16)

His capacity to hold that centrally at such a frightening and unpredictable time reflected the depth of the relationship.
Penny’s experience of admission to a psychiatric ward was also coloured by very frightening visual and auditory hallucinations. She was transferred from the Emergency Department at one hospital to a psychiatric ward at another hospital late at night and this compounded her confusion.

_I sort of walked around but by that time it was night time, so I walked into other people’s rooms not knowing what rooms they were, so I sort of interrupted their sleep. But yeah, and then the nurses dragged me to my room and stuff._ (Penny, p. 5)

Chloe was fifteen years of age when she was detained under the _Mental Health Act_ by Police after a car accident in the country while on holidays with friends. She sustained minor injuries in the accident and was confused when these injuries were not the main focus of her treatment once she arrived at hospital. She did not know how long she had been unwell prior to the accident but said that she had been smoking marijuana with friends for approximately two months. She described the confusion and fear of entering a psychiatric ward on the night of the accident.

_The police ended up taking me to the hospital. I believed I was only taken to the hospital to have my tummy checked. ... I was very nervous and upset being on this [psychiatric] ward because it’s dark and ... I was very upset and crying and the two nurses on that night didn’t understand me. I couldn’t sleep that night. ... I was crying and calling out for my Mum - I should be able to call my Mum._ (Chloe, p. 2)

Chloe’s separation from her mother and being thrown into an unfamiliar environment compounded the impact of her racing thoughts and the collapse of anything that was familiar to her, leaving her feeling alienated and alone in the world. Her level of
distress resulted in her being placed in an isolation room and being given intramuscular medication after which she slept for two days.

David was sixteen years of age when he first experienced hallucinations after using marijuana. His father brought him to hospital two days after noticing David’s confusion, agitation and disordered thinking. He described his racing thoughts as “thinking 24/7” and his physical exhaustion after several days of escalating activity. Despite his confusion he agreed to go to hospital with his father, but said:

_I was scared because I thought they were going to put me in the mental institute. I thought I was going to be like strapped up and stuff, and I was scared about that._ (David, p. 2)

His fear escalated to the point that when he was transferred from the Emergency Department to the psychiatric ward, he feared for his life.

_I thought I was dead, like I thought I had died. Like I went to the hospital and died there, because like, on the drive down there, my heart was beating very fast and as soon as I got to hospital it stopped beating fast. And I thought, ‘Did I die or not?’ And I questioned myself if I died._ (David, p. 4)

David’s disturbed thinking had him interpreting the change in his racing thoughts in a very physical way, and while his cardiovascular functioning had not changed, the strength of these thoughts felt very real and frightening to him. David had been thrown into a situation where he was unable to rely on his physical or cognitive processes to help him to understand the world. The overwhelming nature of his psychotic symptoms resulted in his initial engagement with the staff on the psychiatric ward being of secondary significance to him. His dispassionate descriptions of his first meeting with staff contrasted significantly with the
fundamental challenge the psychosis presented to his being-in-the-world.

*I walked in the ward and the nurse showed me my bedroom and in the bedroom they gave me the medication. And then I wanted to play the video game on the X-Box there and the game looked like it was reaching out to me. ... I heard it say, ‘Oh is this what your future wants to be?’ Like, ‘Is this how you want your future to be?’ And it was like all these colours everywhere and stuff. It was very weird and scary.* (David, p. 5)

David did not register the foreign nature of the ward environment because cognitively and physically he had been thrown into a world where nothing was familiar and the visual and auditory hallucinations were both stimulating and frightening. David gave a very accurate description of ‘thought disorder’, and despite his suspicions that things were not quite right, he sought to understand what this uncanniness was about. This was the first step in locating the work that was needed to deal with these thoughts.

**Locating What Helps**

As discussed in more detail in Chapter Three, the treatment of first episode psychosis has been researched extensively, with an emphasis on early detection and intervention, biological and genetic markers, treatment protocols and pharmacological and psychosocial interventions. The initial treatment of the acute phase of psychosis is primarily psychotropic medications in a safe and supportive environment. For some young participants in this study the discussion about ‘treatment’ initially focussed on the introduction of psychotropic medication. For some this was a relief as the overwhelming and unfamiliar experiences of the psychotic symptoms were unbearable. For others the introduction of medication was
just another reminder that they no longer had control of their relationship with the world. David, whose visual and auditory hallucinations resulted in him being unable to rely on his cognitive and physical processes to help him make sense of what was happening, was relieved when it was suggested that he should take some antipsychotic medication.

...but as soon as we got there [the ward] I was like, oh this is not too bad. And then they said I should take this medication, so I took it and yeah, the next day I was feeling a bit, oh I wasn’t feeling better, but I could tell the medication was helping a bit, yeah. (David, p. 4)

For Max, resisting taking medication was just another way in which he was trying to maintain some control in his life although, even in his manic state, he recognised that there were consequences for not doing so.

You had to take your medicine, although you didn’t really have to, you’d just be in longer if you didn’t! And I’d say, I’m not taking pills. I have a completely straight belief. I pretended that I’d made up a religion and I’m like, ‘Nuh! Against my religion!’ and they’re like, ‘It would be better if you did.’ ... Even now I really wish I protested that a bit more, not because in the long run it would have been better for me, but just because I would have had so much fun doing it [laughter]! (Max, p. 6)

It was only after Max’s mania had receded and he was starting to feel depressed that he was able to accept that he needed help. However the association between accepting help and losing control in his life when he was detained under the Mental Health Act remained strong.

You come to a point when you realise that they are making sense – they make
sense to you. They explain it so well and the doctor was right there and saying, ‘Without even knowing your history I can say to you that you have delusions of grandeur, you have irritability’ and he says all this stuff and I think, ‘my god he’s right’. Yeah [laughter]. You come to the point where you realise that they are saying the truth ... You start taking pills and everything. Oh no, I started taking the pills before they even diagnosed me. But I appealed my detention ... and the lawyer got me out on a technicality. And then they detained me again as soon as I got out [laughter]. God dammit! Let me have a cup of coffee first and then we would joke as well. They got me again and then I tried to appeal that detention but it never happened. (Max, p. 8)

Max used humour to explain the association between the acceptance of treatment and his perceived loss of sense of self and his relationship with the world. His response to his lack of control in the situation into which he had been thrown was to demonstrate his resistance. At times this was through overt breaches of explicit regulations such as banging on the locked door in an attempt to leave which resulted in him being placed in an isolation room and receiving intramuscular psychotropic medication. At other times it was by deliberately engaging in loud behaviour to let the staff know that he could challenge their control.

*I was singing extremely loudly like punk songs against the system. ... And they’re like, ‘Can you please be quiet Max?’ And I’m like, ‘Nuh, I’m not being quiet. If I’m here against my will then they’re going to deal with it!’ And they didn’t stop me. ... They thought I’d shut up after a while but I didn’t. Hours on end, really loud, and it pissed off a lot of people and I didn’t care. (Max, p. 5)*

While Max’s mania was clearly still evident in his actions, his determination to stand
alone and not identify with the Them-world points to his authentic being. Heidegger’s use of the term authentic is not to be confused with the common usage of the word which refers to something as real or valid. Heidegger uses this term to unify the scattered components of being. When one reflects their authentic being, they are recognised for what they are and not lost in the Them-world. However it has been suggested that authenticity is a modification of inauthenticity, or an aligning with the Them-world which arises when one is anxious for one’s own being (Collins & Selina, 1999). In anxiety, the being of human beings is what Heidegger calls uncanny, or not at home and a retreat to the Them-world allows an opportunity to build a sense of security. Hence it is possible for human beings to move between authentic and inauthentic states depending on the levels of existential anxiety experienced. This is most evident when Max and other young people speak of the experience of labelling and stigma in their lives. The struggle to overcome self-stigmatisation as well as the stigma inherent in some practices in mental health settings will be explored in more detail in the next chapter.

Several of the young participants in the study reflected on the impact of medication on their thinking patterns. Most of the young participants had acted in a non-reflective manner prior to coming to hospital, never challenging their perceptual or cognitive experiences despite these being very distressing for some. After being detained by the Police and brought to the Emergency Department of a major hospital, Amy has difficulty recalling her transfer to the psychiatric ward due to the medication she had been given.

_They drugged me up that much I don’t remember getting there._ (Amy, p. 2)

However it was the plunge into the unknown and unfamiliar that caused her most
... they gave me some of these really heavy sleeping pills because I wouldn’t go to sleep. I couldn’t sleep in there! I just couldn’t! I wouldn’t be able to sleep in there. I’d be honestly up until 12 midnight and then they’d still be, ‘Go to sleep, go to sleep.’ And I can’t, it’s not my room. There’s nothing in there that’s mine! I’d never been in there before. I think every night I was in there they had to give me sleeping medication cause I just wouldn’t go to sleep.

(Amy, p. 2)

Joe was accepting that medication was part of his treatment and was eager to take it if it was going to reduce the distressing voices in his head.

I was fine with it [the medication] as long as it helped me, kind of thing. As long as it got me better. And I definitely took it. ... I had to switch medications at one point because one of them didn’t work. I wasn’t getting any better. I was sort of staying at the same level, hearing voices and stuff like that, and I was paranoid sort of thing. And then I got onto a different medication and then it started to work. (Joe, p. 4)

Interestingly, a number of the young people made no mention of medication as part of their treatment in hospital despite the fact that they had been commenced on medication during their hospitalisation and continued to take some form of psychotropic medication at the time of the interviews. What mattered to these young people regarding their treatment was their relationship with their family, their relationship with the other young people during their admission and their relationship with the staff.

This latter aspect is an example of Being-with-others as constituent of Being. We
cannot be in the world in a solipsistic or isolated state, we can only be in the world when we are being-with. Being-with-others is so fundamental to being that it can be taken for granted in everyday life. It is only when the existential anxiety associated with thrownness surfaces that we turn to others, experiencing either support or censure. When these young people and family members are thrown into a world that includes mental illness, they turn to those who are in this world with them for help.

All of the young people participating in the study referred to their relationship with family members as being central to understanding this new world into which they had been thrown. Dan spoke about his security in his relationship with his father and how this helped him to navigate a foreign and sometimes frightening world.

*When I came to the hospital I was with my Dad and I just felt relaxed. Like, I didn’t know what I was meant to think or like why I am here. I kind of knew something was wrong in myself, but it’s not like when people go to rehab, they know they have to get better. It’s just something that I was thinking, like, ‘Yeah I’m here with my Dad. I’m safe. I’m just going to stay and see what happens. ... then we played table tennis. And every time Dad would come we’d play table tennis together and that brought back memories of my childhood because we used to have a table tennis table when I was younger.* (Dan, p. 3)

The innate trust that Dan had in his father helped him to identify positive ways to take control. Dan had a troubled start to his hospitalisation due to physical confrontations with staff and was subsequently moved to a secure intensive care. On his return to the less secure psychiatric ward, his father helped him to understand what was required and to plot a route towards discharge.

*I talked to my Dad. He was like a teacher in a way. He would say, ‘So here’s
what you have to say to get you out.’ ... You know, he’d give me advice about when I’m talking to my psychiatrist, because they’re the way out, they’re the keys to the door. ... He was always coming in and calling. He was like, ‘Alright Dan, how are you going? I’m coming in after work today. Give me a call if anything’s wrong.’ And if anything was wrong I’d always give him a call and talk about it, and he’d solve it so my mind wasn’t worrying about something stupid. (Dan, p. 16)

In addition to his relationship with his father, Dan’s relationship with his brother was also central to his sense of self and the separation from him during hospitalisation was presented by Dan as a significant loss.

Yeah, I actually loved when my brother would come because my brother was my best friend pretty much all my life and we always felt like we were good mates. When I hadn’t seen him, because he didn’t want to come in and see me how I was, and I felt really sad. [Speaking softly] ‘I don’t care man, just come and see me!’ Like even now I get sad about it, because like, it can bring you down if you lose someone that’s so close to you. (Dan, p. 12)

For Penny who was initially diagnosed with bipolar disorder, her daily visits from her parents were the only time when she felt she could show her emotions. This resulted in staff asking her parents to visit less often, a request they declined. An experience during her hospitalisation influenced her decision to limit to whom she expressed emotion.

And I just remember there was this really depressed girl and she was crying and I just like said to the nurse who was sitting next to me, I just went ‘Someone’s crying’, and he just like, yeah, he didn’t really do anything about
it. ... I thought like, you’re supposed to help. But I think they ignored it for a reason but I don’t know why. ... I wanted to do something but I was pretty scared to say anything to her. (Penny, p. 19)

Being thrown into a foreign environment where she could not rely on the emotional support from staff had her also questioning her own instinctive responses to the distress of others. It was in relationship with other young people on the ward that Penny found some comfort. It was with others who have had similar experiences that she felt most understood.

Well it was really cool because there were other young people who were undergoing something like I did, so I found that pretty cool and they were talking to me and stuff. ... Yeah, it was comforting. (Penny, p. 7)

The knowledge that they were not the only ones experiencing these strange and disturbing symptoms was a source of solace to most of the young people, despite some initial fear that they may be exposing themselves to the stigma associated with mental illness. The complexity and impact of this stigma will be discussed in more detail in the next chapter. Sara specifically refers to the issue of feeling judged that influenced her being with others. Her experience of being with professionals was dominated by a lack of trust and her contact with peers through university was more as ‘party mates’ rather than close friends, so her being with others who had similar experiences became even more vital.

Mainly it was good just to talk to people I guess and that’s all hard because I don’t trust anyone around me. But I did trust the other patients in some ways ‘cause they wouldn’t look down on you. ... That was probably the most important thing, that and the medication I guess [laughter]. (Sara, p. 5)
In an essay Max wrote after his discharge, he describes coming to an understanding about his being-with the people he met during his hospitalisation and his introduction into the world of mental illness.

*What isn’t a small price to pay is being detained in a mental institution for well over a month, and having your joyful, gleeful, absolutely fabulous life being locked behind fairly strong doors. Sure it may be fun at first. Destroy the system from within, become a political prisoner ... But then you realise something uncomfortable. Those doctors are making far too much sense. ... And the other political prisoners, detainees, residents, psychos, patients and chemically imbalanced people were really nice. Great people. Inviting, understanding and accepting.* (Max, essay, p. 2)

Dan, aware of the strong support that he has from his family, describes his encounters with other young people who do not have the same level of support.

*A couple of kids that I met in there they’ve been through so much where their parents and ... their family, everything’s disappeared apart from themselves and they’re left to carry it. They would express their feelings and that’s when I guess they’d feel better knowing that someone can understand what they feel.*

(Dan, pp. 4-5)

A number of the young participants spoke about how they managed their relationships with staff and this relationship with staff determined whether they found their hospitalisation useful or detrimental. Most of the young people regarded hospitalisation as having both positive and negative effects. For Sara the ultimate aim was discharge from hospital and her relationships with staff were managed accordingly.
I didn’t trust them. It was because I wanted to get out as soon as possible, and if you want to get out as soon as possible you have to be able to act normally. It’s easy to act normally when you’re not actually in close contact with someone.

Q. So that’s part of the strategy, to keep the distance?

Yeah, and it worked. I was out in two days. But I guess it didn’t work in the long run because I had two more admissions. (Sara, p. 6)

Choosing to be alone or to separate oneself from others is yet another way of being-with-others. For some of the young people participating in the study, keeping to themselves was one way in which they managed the unsteadiness associated with being thrown into a strange and frightening world in which their sense of self was being challenged. For Joe, who was experiencing the voices of others in his very frightening auditory hallucinations, keeping to himself was his way of trying to contain the voice of others until he could find ways of controlling the voices in his head, this is in itself a way of being with others. He was very accepting of the need for medication but also found that there were ways that he could control the thoughts.

I knew I had to get better, yeah, to stop hearing voices, to control the thoughts, yeah. ... I just figured it out myself, like just to control the thoughts kind of thing. I was just basically sitting around just trying to control it because I’d got used to it. It was like I was getting these images pumped into my head was kind of happening, and I was basically trying to stop some of them. And eventually, yeah some of them do get through still, but I just ignore them. (Joe, p. 5)

Yeah, I snap my fingers to make the thoughts disappear. And from there, I blink my eyes, something like that, just to make it disappear. I distract myself, just
get my mind active kind of thing. (Joe, p. 8)

Here Joe is describing the Cognitive Behaviour Therapy (CBT) techniques of thought stopping and distraction as an initial way of controlling the unwanted voices. He knew that, for him to go home, he needed to understand how he could control his being with these voices.

For Max and Penny, being able to engage with their artistic sense of self while in the psychiatric ward enabled them to retain constituents of their being-in-the-world that is not dominated by mental illness. Max was involved with art work and writing poetry and a novel, while Penny tried to deal with the slow pace of the ward environment by doing drawing in the art classes provided, struggling to find inspiration for her work.

I like drawing but I had no assignments, like no art assignments so it was kind of like, what do I draw? (Penny, p. 7)

Being thrown into the environment of the psychiatric ward was so foreign to her, that it was not until a chance encounter discussed further in Chapter Six that she was able to re-engage the strengths and skills that characterised her being-in-the-world and her hopes for the future without being dominated by the experience of mental illness.

Feeling safe in this foreign environment into which they had been thrown was all of the young participants referred to in some way. What does it mean to be safe in an environment where we have limited capacity to control? For some, being thrown into the controlled environment of the psychiatric ward represented containment and certainty compared with the unpredictable and frightening nature of their psychotic symptoms. For others, that sense of containment increased their concerns about safety and they level of control they had in their lives. David, whose disordered
thoughts and perceptions had him questioning whether he was still alive, appreciated an environment which would counter these distressing experiences and likened it to an environment which for him was completely safe.

_Because when I was out and I had psychosis I felt like everyone was looking at me, and I thought, I thought, I got really panicky, yeah. And in the psychiatric ward, it’s like one big house thing. It’s sort of like nice and calm in there, like it feels like normal ... because it felt like I was at home, like in a safe place._ (David, p. 7)

This sense of safety was not just about ward milieu, but had its foundation in David’s relationship with others and particularly the nurses who spoke calmly to him, helping him to talk through his feelings of panic and uncertainty, and reduce his anxiety. The concept of safety in the context of the space of a psychiatric ward will be elaborated further in Chapter Eight.

**Summary**

The forming and maintenance of social relationships, whether with friends or others who have had similar experiences, has been found to be a crucial part of managing and reducing symptoms. The long-standing practice in psychiatry has been to regard people experiencing mental illness as unable to develop and maintain social relationships (Schon et al., 2009). The young people in this study clearly identified that being with others is an essential aspect of understanding the challenge to their sense of self that psychosis brings and the anxiety related to being thrown into a world involving mental illness and the foreign environment of a psychiatric facility.

The descent into psychosis, which can take place over many months, is a traumatic and life changing experience. The young people experiencing their first episode of...
psychosis are thrown into the foreign space of the psychiatric ward in a traumatised state. Their only experience of such an environment comes from the media or the movies.

The young people have their sense of self destabilised by the symptoms of psychosis, resulting in fear and uncertainty. They seek to address this uncanniness with the support from their parents. They look to the staff for support but this is not always effective as the messages they get are mixed. The staff too, are unsteady in this new relationship, and they are not always clear with the young people and family members or with other staff members about the best way to deal with this experience.

In the next chapter I go on to explore how the experience of hospitalisation confirms some of the worst fears of the young people and their parents or siblings. The next chapter identifies how difference, isolation and being with others produced the sense of stigma and alienation. Nurses sense the difficulties lying ahead and are aware of how stigmatisation plays out.
Chapter 6: Limitations of Horizons

Introduction

In the previous chapter discussion focussed on the young participants’ experience of becoming unwell, their pathway into hospital and their experience of treatment, and the challenge this presented to their being-in-the-world. The effects of this unexpected and frightening illness also impacted on family members, challenging their understanding of themselves as parents and leaving them unsteady and anxious in their world. The nurses too experienced the unsteadiness and existential anxiety related to each new relationship.

The Heideggarian concept of thrownness that was introduced in Chapter Four and discussed in more detail in Chapter Five, continues to be applicable here in this discussion about the impact of social and cultural beliefs and attitudes towards mental illness on the participants’ being-in-the-world and future possibilities. The familiarity of the everyday world and the capacity to dissolve into the Them-world is stripped away, and the young people and family members are thrown into a world that is frightening and isolating. That world is one in which the stigma associated with mental illness has influenced both the young people and family members involved in the study. They are confronted by their own beliefs about mental illness before being exposed to the stigma that is embedded in institutions and community.

Labelling of the Other

Stigma incorporates the processes of stereotyping, prejudice and discrimination, but also transcends these by the use of psychological processes that ensure that the targeted individual internalises a diminished view of self. Being diagnosed or
labelled as mentally ill results in disadvantaged social circumstances, for instance, in terms of employment, education, social functioning (Wright, Gronfein & Owens, 2000, p. 70).

For most of the 20th century, the leading theoretical conceptualisation of child mental health problems has centred on problematic parenting. While concepts such as the ‘schizophrenogenic mother’ may have lost some currency in its overt form, the practice of blaming parents remains strong. In the context of such practices, the shame of acknowledging your child’s mental health problem limits the pursuit of assessment and treatment. Therefore, stigmatisation is a significant consideration in child mental health (Hinshaw, 2005, p. 715). Stigmatisation counteracts the chief principles of early intervention in psychosis, which are the early identification and treatment of psychotic symptoms.

In our society a range of social issues and individual traits are stigmatised, such as racial minorities, people who identify as gay or lesbian, and homelessness. Most of the research on stigma focuses on the stigmatisation of racial and ethnic minorities (Heatherton, Kleck, Hobl & Hull, 2000), and while there has been some amelioration of overtly racist attitudes over the last century through community debate and public policy, the more subtle inflection of racism continues in both individual and institutional forms.

In contrast, the stigmatisation of mental illness remains quite direct. While there have been a number of media campaigns in Australia aiming to counteract stigma and raise awareness, such as the Change Our Mind and Beyondblue campaigns, and targeted programs such as the Mindmatters national mental health initiative, there has not been the same level of social embargo placed against scorn or disparagement.
in relation to mental illness. “Having a mental illness is one of the most overtly stigmatized attribute an individual can have, rivalled by substance abuse and homelessness” (Hinshaw, 2005, p. 716).

Walton (1995) hypothesised that deinstitutionalisation and the resultant increased exposure of the wider community to people with psychiatric illness could lead to a decrease in the stigma associated with mental illness (p. 138). Notwithstanding such a possibility, part of the reason why the stigma surrounding mental illness remains so ingrained is that the social cognitive processes where ‘outgroup members’, defined as those who live outside the boundaries of the dominant group who are linked by family heritage, community or shared values, are all seen as alike. At the same time strong cultural messages via the media or word of mouth result in negative messages about mental illness to extend so thoroughly throughout the community that they have become overlearned and part of an automatic or unconscious response. The biases are implicit and may not even be recognised, therefore making them very resistant to change (Teachman, Graspinski, Brownell, Rawlins & Jeyeran, 2003). Although there is limited evidence about the extent to which young people adopt these negative biases about mental illness, it is suggested that they are likely to be learned early given the pervasiveness of these biases in the community. In a review of animated children’s television programs it was found that 50% included a depiction of a character with mental illness. The identified characters played either a comic role in which they were seen as illogical or irrational and were frequently laughed at by other characters, or an evil role in which they were seen as aggressive and involved in violent acts such as kidnapping or murder. The vocabulary used to describe the characters was negative and disrespectful, with terms such as crazy,
loony, twisted, and nuts being frequently used. The conclusion drawn from such studies of media portrayals is that children learn to think these terms are acceptable and even humorous, and that this contributes to children learning to separate and put down those with mental illness by bullying or harassment (Wilson, Nairn, Coverdale & Panapa, 2000).

Six dimensions of stigmatisation have been identified and these are aesthetics (physical appearance), disruptiveness (including externalising disorders), concealability (can the disorder be hidden), chronicity (mental disorders are assumed to be lifelong), threat or peril (media portrayals of mental illness are biased towards violence and dangerousness), and controllability (symptoms of mental disorder are often seen as chosen and controllable) (Jones, Farina, Hastorf, Markus, Miller & Scott, 1984). The recent focus of research on defining the genetic or biological markers of mental illness offers a potential pathway to reducing the stigma by associating mental illness with bio-genetic medical models. However, when mental illness is seen as related to flawed genes, the potential for those with mental illness to be “...viewed as a separate, inferior, even subhuman group” (Hinshaw, 2000, p. 717), further entrenches harsh and stigmatising attitudes towards those with mental illness. Much of the research regarding stigmatisation has focussed on the impact that causal explanations have on social distance. More concerning, it seems that in a meta-analysis of research done over the last 50 years, the majority of causal explanations, that is whether genetic, biochemical, disease or adversity, producing such explanations has limited if any impact on the social distance kept from those who are perceived to be mentally ill (Jorm & Oh, 2009).
Being Confronted as the Other

In the context of such strong and entrenched social attitudes, for young people who are experiencing their first episode of psychosis, their symptoms often not only challenge the perceptions of those around them, but the young people themselves are also aware of the stereotypes and stigma that society would attribute to their behaviour. All of the young people who participated in the study referred directly to the stereotypical understanding of mental illness that exists in the community.

Sara was eighteen years old at the time of her first episode of psychosis. She sought treatment at the Emergency Department at a local hospital, but escalating fear drove her to leave the hospital and seek the assistance of her Aunt. She subsequently returned to the hospital with her Aunt and was detained under the Mental Health Act. Sara was very aware of the stereotypes that would be attributed to her behaviour and reacted angrily to these. In describing her interactions with the psychiatrist and nursing staff soon after admission, she refers to her impression that she represented a perceived threat or dangerousness even to staff.

*It was just weird that everyone was treating me really delicately, when I was, okay, this is weird, why are you talking to me like this? ... like I was going to explode or something or like it would be like, ‘everything’s going to be okay’. You know when you see people on the TV and it was like, ‘Okay, just drop the bomb, just drop the knife.’ I didn’t have a knife. I’m a tiny little girl you know. It’s not like I’m going to do anything! But I thought it was quite funny. Actually, well I think it’s funny now but it just confused me at the time.* (Sara, p. 2)

Media portrayals of mental illness in television and film as well as media reports of incidents of police interaction with mentally disturbed people place an emphasis on
violence and danger to the public. These stereotypes were an anathema to Sara’s perception of herself as a person who had won awards for highest academic achievement at school and was enjoying similar success at University. To be approached as someone who is potentially dangerous compounded the confusion created by erratic thoughts and escalating activity.

Media portrayals of mental illness also influenced parents’ initial perceptions both of hospitalisation and psychotic illness. Julie, whose son David had been admitted to hospital with agitated behaviour after smoking marijuana, described how her experience of moving into the unfamiliar environment of a psychiatric ward was coloured by her only exposure to such an environment – through the movies.

_We didn’t know what to expect, you know. I just thought it might be like “One Flew Over the Cuckoo’s Nest” [Nervous laughter]._ (Julie, p. 2)

And later when describing how she learned about the illness of schizophrenia, she was again challenged by the stereotypical depictions of mental illness.

_Yes because when I was looking up schizophrenia and what happened ... we thought of the movies with the mad men in it, and like “Jekyll and Hyde”. When you hear of schizophrenia and psychosis, you think that someone with schizophrenia that they’re absolutely mad, but it’s not the case._ (Julie, p. 12)

The invitation for both the young people and their families to have this label of psychosis or schizophrenia dominate their sense of self was very strong. However, the majority of the participants in the study openly resisted this. Julie had prior experience of resisting the domination of diagnosis when David had been diagnosed with Attention Deficit Hyperactivity Disorder and Learning Difficulties and medication was recommended. She and her husband declined this and sought
alternative therapies and educational opportunities for David to develop his skills.

The young people were also confronted by their own beliefs about mental illness and this challenged their sense of self and how they see themselves in the world. Max described his first entry onto the Ward accompanied by Ambulance officers:

*I met all the other people [on the Ward] and yeah, the other people I was a bit unsure about – they were sort of a bit psycho. ... I wasn’t scared ‘cause at that point I was so manic that nothing could touch me. I was just a bit, well if people visit they’re going to think I am as well. I couldn’t have that! I have a reputation to uphold [laughter then pause].* (Max, p. 5)

And later:

*They put me on this holiday program and you go and do activities, and it’s all movies and stuff just with other crazy people. I thought they were so less able than me. I really did think I was superior to all the rest of them.* (Max, p. 9)

In an essay Max wrote after his discharge he describes coming to a realisation that he had more in common with the other people on the ward than he realised.

*Ouch. Hang on. I was just like them, and more importantly, they were just like me.* (Max, essay, p. 2, original emphasis)

Amy, whose detention and transportation to the hospital had been traumatic, tearfully explained her distress when confronted with her own underlying beliefs about mental illness and how this challenged her Being-in-the-world:

*I just didn’t know what was happening and they moved me upstairs into a room with all these other people and they wanted me to stay the night and I didn’t*
want to stay so I got angry with them. ... Yeah, fruit loops like me! Some were in there for overdosing, suicide, seeing people that aren’t there or voices that aren’t there – yeah, fruit loops! ... There were only two good people in there who were not so bad. The rest were weirdos. (Amy, pp. 1-2)

Despite having just described her own experience of visual and auditory hallucinations, the negative messages about mental illness have been so overlearned they have become part of Amy’s automatic or unconscious response to her own condition.

The experience of sudden stigmatisation is painful not only because of their confusion about their identity, but from knowing exactly how society sees them. These young people have experienced the Them, the collective understanding and expectations of society, and they know all too well what they have become. The power of the They lies in the difficulty in identifying specific elements, with individuals or the human being dissolving into others and becoming others, and others becoming part of the human being (Collins & Selina, 1999).

The everyday way of being in the world is marked by Heidegger as either an undifferentiated or inauthentic state of being. We are in an undifferentiated state when we unconsciously follow the They, whereas in an inauthentic state we consciously make decisions to fit in with others. The young people’s capacity to embed themselves in the everydayness of the They is withdrawn, leaving them ostracized and alienated.

Stigmatising practices are not just from those who other, but are also entered into by those who are stigmatised. They are confronted with, and need to overcome their own socialisation. The social being that has been constructed by being thrown into a
world in which mental illness is stigmatised is part of their embodied existence, so when they first experience psychosis it results in them denying their own sense of self. The path to interpreting and understanding this new world into which they have been thrown is long and complex.

The young people in the study often used humour to differentiate themselves in some way from the shameful differentness that is stigmatised by society and separates them from the They: the aberrant behaviour of one with mental illness. This reflects what Goffman calls the ‘normal deviant’ who, being part of broader society, mirrors both the stigmatised values and the experience of a person with mental illness.

... a stigmatised person is first of all like everyone else, trained first of all in others’ views of persons like himself, and differing from them first of all in having a special reason to resist stigma derogation when in their presence and the special license to give voice to it when in their absence. (Goffman, 1962, p. 160)

The self/other and normal/deviant dichotomies and the paradoxical contrasts that are prevalent in the debate about stigma and mental illness add to the confusion for young people experiencing first episode psychosis, challenging their sense of self and their resistance to the pressure to have their illness experience dominate their identity. The dualism of self and other and its impact on power relations and the opening up of space in which young people can be heard will be extended in Chapter Seven.

Sara tried to manage the potential stigmatisation of having a mental illness by keeping her hospitalisation a secret. She saw herself as a high achiever, a learner, the person who goes after her own goals, and having a mental illness did not fit with that
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sense of herself.

I am not what you would call someone who gets psychosis, you know. It’s not like I’m a heavy drug user or anything. I’m doing psychology and I have an arts degree. I guess I kind of split the two and to be able to keep being the high achiever. I’m up for a couple of awards and a finalist in some really good awards but I’m here today talking about psychosis and having been in hospital for that kind of stuff. I go to services to be able to afford housing needs in association with normal life but then I go to things like young professional meetings. ... I keep this stuff separate so I can be a high achiever, but I’m also in a very scary place and it affects how I’m feeling and my ability to learn and stuff and all that kind of stuff. (Sara, p. 8)

Sara’s stereotypical understanding of the causes of psychosis significantly impacted on the support she sought while she was in hospital. In order to maintain her sense of self as a high achiever, Sara chose not to tell people that she was in hospital following her first episode of psychosis and while she acknowledged that this had both positive and negative effects, she was not prepared to incorporate the experience of mental illness into her being-in-the-world.

I think it was good in respect, I would probably do the same thing now if I went to hospital. I wouldn’t tell anyone because you worry about it, you worry about the gossip that’s going around. ... Okay, if I had people visiting me it might have broken up the monotony of the place and might have kind of made the situation more real to me because both my worlds were colliding together. But it wasn’t like that. I kept them completely separate. (Sara, p. 8)

Sara is painfully aware that if she incorporates her experience of mental illness into...
her authentic sense of self she fears she will compromise her future horizons.

Ambivalence is a common attribute in stigmatising responses. People are likely to feel commiseration and concern for those labelled with a diagnosis of mental illness because they recognise that their life is difficult. However, the unconscious biased associations regarding mental illness that are learned from early childhood can also lead to the desire to distance themselves from the stigmatised person. This ambivalence is reflected in some of the comments made by nursing staff. In trying to explain why a young person with psychosis may be treated differently, Nicola, a Registered Mental Health Nurse with four years’ experience, reflects on how fear impacts on the nursing care delivered.

“There are admissions that I can think of and I think they would probably rave about the care they received because they did get that holistic care, whereas other kids, and generally psychotic kids because people are fearful of them and believe they might not be aware of what’s going on so it doesn’t matter, whereas generally they are more clued in and they can remember some amazing things. Oh God [laughter], and the way they get spoken to – it’s so different to someone who came in for something else. ...someone who is psychotic would be treated very differently to someone who has come in with say an eating disorder because they look so weak and fragile. (Nicola, p. 11)

Nicola’s awareness of the discrepancy in attitudes and care for young people with psychosis and the dilemma this raised for her as a nurse was a theme that she explored during her interview. She found it challenging to align the need to give directions and use behavioural management strategies with giving the client choices and including them in their treatment, both of which she believes are fundamental to
nursing practice.

Most of the nurses commented on the impact that the young people’s experiences and behaviour prior to admission to hospital had on family members, however the way in which this was interpreted differed significantly. Patrick, a Registered Mental Health Nurse with 10 years’ experience, recognised how frightening the process of admission is for parents:

... all of a sudden there are these significant changes that happen for their child and they’re not the normal changes that parents would anticipate ... their child suddenly loses touch with reality – it’s not something that parents normally see, and often the events leading into hospitalisation can be significantly traumatic for parents to understand. I remember speaking to a mum who was so overwhelmed by the fact that her daughter was found wandering through [a shopping mall] with no clothes on except a pair of football socks. And you know, she found that incredibly daunting and overwhelming. And it is, it would be an awful experience for any parent to understand. (Patrick, p. 8)

Patrick recognised that this parent had been thrown into an experience that was completely unfamiliar and frightening and that it was a challenge to her Being-in-the-world as a parent as well as her understanding of her daughter’s relationship with the world. All that was familiar had fallen away, and her daughter’s behaviour had stepped away from what was acceptable in the Them world, potentially leaving her alienated from what was previously taken for granted as her world.

Some nurses commented on the duration of untreated psychosis in terms of what it reflected about the parents’ response to their child’s condition. Anne, a Registered
Mental Health Nurse with three years experience, in describing her recollections of working with a sixteen year old young woman who had been admitted for the treatment of psychotic symptoms, clearly identified the inaction of the parents as a source of concern.

*She was one of the first really debilitated kids who came in with first episode psychosis that I had ever seen really. And she had been at home like this for six to eight months. Her parents were just directing her to get dressed and taking her to school and off she goes. It was very strange really when talking to the parents and they were reflecting on how long she had been like this and they hadn’t actually done anything about it or taken her to the doctor or anything. It was quite scary.* (Anne, p. 3)

While the duration of untreated illness (DUP) is often discussed in terms of the need for early identification and treatment of psychotic symptoms, the reality for many families is that feelings of guilt, shame and embarrassment have a big impact not only on parental help seeking behaviours but also on their relationship with their child. The overt blaming of the parents that developed with the psychoanalytic model of mental health continues today and is reflected in the way parents feel they are treated when their child is hospitalised. This way of thinking characterised Anne’s relationship with this young woman’s parents throughout her admission. The limitations placed on their visits to their daughter and a disregard exhibited for their concerns about her education reflected this nurse’s lack of connection or relationship with them.

*She didn’t appear upset at all. She was aware she was in hospital, but to begin with her parents were there all day every day. ... And on the Ward we have*
quite a few activities that we have for them during the day, and her parents wanted to be there all the time and it was quite difficult to separate them. So we popped some limitations on when Mum and Dad could come in. (Anne, p. 7)

She was extremely disorientated, distracted, unable to concentrate. Anyone walking down the street would look at her and go, “Oh, right, there’s something not right with her.” But Mum and Dad were still like bringing the school work. They were getting upset about it. So in the end, they would bring the school work in and we would put that aside. (Anne, p. 9)

The impact of stigma on the family members of those with a mental illness has been discussed in the literature for many years, and its impact on the level of acceptance by mental health professionals and their willingness to acknowledge their relative’s mental illness has been documented (Wahl & Harman, 1989; Heatherton et al., 2000). The overt use of power in Anne’s management of this situation and the tacit assumption that the professionals’ decisions would override those of the parents had serious implications for the development of productive and collaborative relationships between staff and parents.

While aspects of the psychoanalytic model have been discussed in Chapter Two, they become particularly relevant when considering the impact of stigma on family members and the practices that sustain it. While psychoanalytic concepts such as the ‘schizophrenogenic mother’ do not have the same currency today as when they were developed in the 1950’s, there remains a tendency to look to the mother/child relationship to explain the psychotic illness in some way. Practices such as limiting parental visiting reflect a critical attitude towards parents and implicitly place blame
on them for their child’s illness or other failures such as getting medical attention or to understand how the medical team wanted to control the young person’s environment.

All of the parents interviewed in this study reflected on such limitations placed on their visiting rights. They responded to these in different ways. Sue, after signing detention papers for her son in very difficult circumstances and seeing him transported to hospital by ambulance and police in attendance, was asked by staff on the ward not to visit for a few days.

Yeah, so I didn’t go in there for a couple of days because, you know, I think they wanted him to settle down and stuff like that. (Sue, p. 4)

Despite being very distressed herself following her son’s detention and having no sources of support at home, Sue complied with the staff’s request and waited for three days before she visited him. As a parent, Sue is co-stigmatised yet is not offered any help to deal with her distress.

Pam, for whom English is a second language, explains her response to the request that she and her husband limit their visits.

During her time there, the nurse and the doctor didn’t want me and my husband to come there too much. They explain, when you come here she is happy, she asks about her friends, you bring her things that she likes. After that, when you and your husband go home, she is upset and she feels alone. That is very hard for the doctor and nurse to level her moods. They want her to have even moods.

Q. How did you find that? What was it like for you to hear that they didn’t want...
you to come in too much?

I didn’t care – I just go there! [laughter] I know if after work I didn’t go to see her, I couldn’t sleep. I worry too much. (Pam, p. 5)

For Pam her overwhelming concern for her daughter and her strong belief in her role as mother overrode her need to comply with requests from authority figures. She demonstrated this strength of belief later when describing the impact of cultural explanatory models of mental illness within her community.

I have a friend from my country who believes in the supernatural. Before coming to Australia I lived with my mother-in-law who has since passed away. And now something happened to my daughter, like she talked non-stop. And my friend says my mother-in-law has gone into her body and made her like that. But I don’t believe that. In my country some people believe that dead people can come into people and make them do things, but I don’t believe that. ...

When the first doctor said she was using drugs, I thought how could something so scary happen to my family? So scary, so scary! So when my friend said maybe your mother-in-law made her like that, wow, that time was so difficult! After the doctor at the [name] hospital explained and comforted me, I understood. (Pam, p. 4)

Pam was not only confronted with the challenge to her being-in-the-world as a parent, her historical and cultural understandings were also being challenged, and the stigma related to the first doctor’s assumption that her daughter’s behaviour was directly connected to drug use was overwhelming. She related an historical experience that helped her to challenge the strong cultural beliefs about mental illness in her community.
When I was in my house in [name of country] it was beside the market. I would see a lady with no clothes wandering. A few months later she got pregnant. There was no help, no government help. After that I never see her again. And if something happened to my daughter, I was so worried that no one can help her, just God. And I talked to the priest at my church, and he says just pray for her. And when I talked to the doctor he said that many people have sickness like that, so don’t worry. But now I still worry that if the medicine stops that she will get sick again. (Pam, p. 5)

Another psychoanalytic concept that is often used in mental health settings is splitting, or causing a rupture or division in the staff team. In adult mental health the term splitting is used to refer to the manipulative and unpredictable behaviour patterns that are observed in people diagnosed with Borderline Personality Disorder. In child and adolescent mental health this terminology is most often used to refer to the manner in which parents interact with different staff members which is seen as an attempt by the parent to control a situation. The concept reflects the power dynamic between staff and parents and results in a critical attitude towards the parents and often a reduction of information giving or communication. Nicola, a Registered Mental Health Nurse with three years’ experience, found she was criticised by her colleagues for privileging a mother’s right to information about her son over the maintenance of the power differential that had emerged.

Like this one family, when they left their son was extremely agitated and mum was really, really distressed about leaving. As soon as they left he was fine, there were no problems, so I just rang home and said, ‘Look I just thought you’d like to know that he’s okay, he’s settled.’ And mum was really appreciative. When I was handing it over [to staff on the next shift] I got
absolutely blasted for that! ... They said I would be encouraging staff splitting [laughter]. We were having some problems with this mum anyway and there was some splitting going on, but she was still a mum who was distressed when she left and she had a right to know. ... Would you do that for other clients was the comment, and I said well yes, I would do it on a general ward, I’d do it here, I’d do it babysitting! It’s just what I would do! ... I really had to justify why I had done that, almost to the point where I think well next time I won’t even tell someone I’ve done it! (Nicola, pp. 9-10)

Nurses, too, are pressured to comply with the microcosm of the Them world that is the world of psychiatry and mental health nursing. Within that world, the being of everydayness is prescribed by the They that includes policies and procedures, evidence based practice, the Diagnostic & Statistical Manual of Mental Disorders IV (DSM-IV), and that specific ward culture. Much of that which is prescribed by the They is not spoken about overtly, which makes it difficult to challenge. Nicola does not step away from the stigmatising concept of splitting, but instead chooses to focus on reducing the distress of the mother with reassurance and information.

The nurses also noted the correlation between the stigma of mental illness and drug taking among those in the broader systems surrounding the young people with first episode psychosis, particularly when engaging with school personnel. Patrick expressed frustration at the ingrained stigma directed at young people experiencing psychosis.

_The community is not interested in knowing the effects of a psychosis. Everyone thinks that kids who end up with psychosis because they use drugs! ... When I get consent to speak to schools, I used to say to the Principal or School_
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Counsellor, ‘Fred’s not going to be at school ... because he’s in hospital.’
‘Okay, so what’s Fred in hospital for?’ ‘He’s got an acute psychosis.’ ‘Oh, we always thought that Fred used drugs.’ ‘Oh no, Fred never used drugs at all you know. We’ve done drug toxicology tests and there’s no history of it. But there is a history of psychosis.’ ‘Oh no, we think it’s still drug related.’ (Danny, p. 4)

All of the young people commented on the limited contact they had with their friends during their hospitalisation with some ambivalence. While seeing friends was seen as a distraction from the monotony of the ward routines, it was also a reminder of the stigma associated with being mentally ill. Max clearly identifies the dilemma he faced not only with his friends but with visitors to the ward generally.

*Well my friends came, about four of them came. We didn’t talk about ‘issues’.
We talked about the stuff that we would normally talk about. That was after I was manic, once I came down and they came to visit me. It felt weird them being there to see me in an institution and I thought, ‘Oh crap, now they’re all going to think I’m crazy!’ ... It was humiliating at times cause visitors come and they look at you and they think, ‘I wonder what he has’ and just sort of keep their distance around you. Yeah, I got ticked off.* (Max, p. 11)

The young people were adjusting to the challenge to their sense of self as a person with a mental illness at a time when their relationship with their peers assumes paramount importance. The relationship with peers is a key element in identity development during adolescence and this personal identity becomes the basis for the individual’s relationships. Separation from their friends at this crucial time has the potential to build and add to the stereotypes regarding mental illness, leading to isolation and further limiting future possibilities.
Penny, who had many friends prior to becoming unwell, acknowledged the support she received from the other young people in the psychiatric ward, but she missed the support of her friends. Her parents had asked her friends not to visit on the advice of the staff.

*If I had a friend around they could make me laugh and stuff. It’s a pretty scary situation for being in here and away from my family. A friend could help me and talk to me about it.* (Penny, p. 7)

The nurses talked about how the stigma relating to mental illness would impact on the young people experiencing first episode psychosis long after they were discharged from hospital.

*...it’s a dilemma, the general thing that happens ... is when they are actually discharged, these poor kids not only have to then process the fact that they’ve had a psychotic episode, they have to process that half of their school peers aren’t going to talk to them anymore because they’re weird. They’re not only disconnected from reality in their psychotic state, now they’re disconnected ... because of the stigma of the illness that they’ve had, and that’s just, it’s heartbreaking for the kids.* (Danny, p. 2)

The nurses spoke to the dilemma they experienced in balancing the recognition that peer relationships play a key role in young people’s development, with the reduction of environmental stimulation that is seen to be important in the amelioration of acute psychotic symptoms (Early Psychosis Writing Group, 2010, p. 50). To emphasise how this discourse is taken up, some studies recommend that young people who are distressed by the experience of psychotic symptoms “…benefit from a ward environment that reduces environmental chaos” (Orygen Youth Health, 2004, p. 60).
The idea that engagement with friends and family contributes to ‘environmental chaos’ and is therefore detrimental to the recovery of the young person perpetuates and reproduces the stigma experienced by family members and friends. Being-with-others, being in relationship with others is core to our being, and when it is denied and portrayed as central to treatment, such measures impact on the young people’s being. In addition to being thrown into this foreign world of mental illness, they now have to understand and cope with that world without the relational supports on which they previously relied. This practice does not confront or challenge the stereotypes that exist in the community regarding people with mental illness and it forces young people in this situation to limit their friends to fellow sufferers.

**Getting a Diagnosis**

Receiving a diagnosis of psychosis or related illness challenges the young participants’ sense of self and each responded in different ways to this new information. For some it was a relief to understand what was happening while for others the diagnosis reinforced their experience of thrownness into an unfamiliar world and they responded either with despair or anger. For Penny receiving the diagnosis of bipolar disorder was distressing, with her only experience of mental illness had been through the media. She was given this information by a very sympathetic doctor who aimed to reassure her about her future despite the diagnosis.

*It was my first time going there so I didn’t know what to expect. And then when I was fully well they told me what I had which was bipolar at the time and I just cried. ... I remember that I had that diagnosis and I said to the nurse, ‘You guys think I’m a crazy girl’ and then she said, ‘No, you’re a beautiful girl.’ [crying]. ... Well I didn’t know what was going to happen to me, I only*
hear it on TV and stuff. When he told me that, well obviously I was really upset and I didn’t know what it was really. I just thought it was a really terrible mental disorder, so I was really scared. ... [The doctor] he said lots of people overcome this and maintain a normal healthy life. (Penny, pp. 5-6)

Penny fears that her relationship with the nurses, which she found to be a very positive during her admission, would be changed. She was once again experiencing the anxiety of being thrown into the world of mental illness, a world of which she knows little. She is aware of the stigma associated with the diagnosis she has been given and she seeks reassurance that her relationship with others will not change.

Amy’s confusion about her diagnosis during her hospitalisation fuelled her anger over her loss of control.

To be honest when I was in there I had no idea why I was in there. They never even told me until I got out what my diagnosis was. I didn’t have a clue. The only people who really knew were my parents and they still hadn’t told me. ...

[The doctor] says to my friend ‘It’s like a broken bone, it’s in a cast. It takes time to heal.’ That’s what they said! [laughter]. I had no idea what they meant.

I mean I have no broken bones! It just made no sense to me. (Amy, p. 6)

Her own description of her problem was that she was feeling “very lost”. During her time in hospital she remained unsteady about her sense of self, and that unsteadiness extended to her being-with-others and her being-in-the-world. The fear and paranoia that characterised her experience prior to coming to hospital, remained with her throughout her admission, leaving her too scared to leave the house once she had been discharged. At no time during her hospitalisation did she feel that her understanding of what was happening for her was acknowledged or understood by
Sara was also baffled about her diagnosis while in hospital. She underwent an assessment the day after her admission when her capacity to function was significantly impacted by sedating medication.

_The assessing psychiatrist came in and talked to me ... and when they said, ‘Oh, we’ve got it in time’ and stuff like that, and he said you can probably go home in the next couple of days. ... I thought, got what in time? I don’t know. I had no idea about any diagnosis at all until two months later when my psychiatrist wrote to another person, another organisation for referral and I had to give them the note._ (Sara, p. 7)

Sara had a very clear understanding of what was happening to her and this was significantly influenced by her historical and cultural experience of being in the world. Her social understanding of the purpose of hospital as a place to get well and her lack of recognition that there was something wrong reinforced her need to get out of hospital as soon as possible.

_I probably made sense of why I was in hospital as in I just had a ‘funny turn’ [giggle] which is part of my grandmother’s ways. Just that I’d made some wrong lifestyle choices and that it was more like a wake-up call and to change my ways._ (Sara, p. 7)

Both Sara and Amy verbalised alternative ways of conceptualising their current being in the world in ways that appeared to be a complete mismatch to the dominant psychiatric diagnostic categories, and yet were also opportunities for staff to help them to name and understand this new way of being in the world into which they had been thrown.
Dan initially fought against the diagnosis he was given, not wanting it to dominate his sense of self.

_They said ‘You’ve had a psychotic episode’ and then further on then they’d say, ‘You’re schizoaffective.’ ... I tell them to fuck off – I don’t want to hear that! You know, I don’t like being labelled as something that I’m not. But of course now I understand that I’m in a psychotic way when I’m in hospital, but now I’m out of it I’m normal sort of thing. When they had these little meetings, just talking about how I’ve got psychosis and just go over it and over it and saying what it’s about and stuff. And I know myself like, yeah I can accept that I’ve got it but, seriously, do you still have to keep going on about it every time we have a little meeting!_ (Dan, p. 4)

He used humour to challenge the process of being labelled by others, referring to the detached and clinical way that a diagnosis was made and communicated.

_When I think of how they figure out what you are and stuff, they’re all like a little group of school children where they talk behind your back in the back office [laughter]. And then they all come to a conclusion. ‘Yep, he’s got psychosis. Yep. Nup, he’s not psychotic anymore, he’s schizoaffective. Alright, then let’s tell him.’ And back to school! That’s what they do._ (Dan, p. 6)

Dan refers to the stigmatisation embedded in the practices involved in the process of arriving at a diagnosis and the tacit assumption that the decision of the professionals adequately explains the young person’s experience.

Chloe also struggled with the label that was given to her on admission to hospital. She compared her own experience of becoming unwell with her witnessing of others in the ward and found no similarities. In her experience schizophrenia was linked
with physical aggression towards others and this did not fit with her sense of self.

*When I first went in there [the psychiatric ward] they told me I had schizophrenia. I thought I was just very stressed out and things were not going well for me. Like I didn’t know that I had psychosis but I did. But I wasn’t absolutely sure because there were other people there who had psychosis and we were nothing alike. ... I’m not the type of person to get angry at something. I just couldn’t see myself schizophrenic.* (Chloe, p. 6)

The process of getting a diagnosis is one that has a significant impact on these young people’s understanding of who they are in the world. The use of terminology such as being a ‘psychotic’ and a ‘schizophrenic’ totally encumbers these young people’s sense of self and they take this with them into the future. To have an illness implies that it is one aspect of your being and that it can be overcome, but to be an illness discounts all other constituents of being and it becomes a life-long label.

**Looking towards the Future**

The future is not something that is simply not-yet now waiting for our arrival on the “path of time”. ... Rather the future is meaningful to one because one goes toward the future. To have a future means to expect, to anticipate, to look forward to. Hence the future is meaningful. (Gelvin, 1989, p. 179, original emphasis)

Thrownness is being-in-the-world in a way that is not of our choosing. But at the same time we project forwards to this or that possibility for our being. But the experience of thrownness itself restrains possibilities due to the context or limited skills or knowledge. So our being in the world is a tense, uncertain struggle between thrownness and possibility. For young people experiencing their first episode of...
psychosis, the stigma associated with mental illness is very much part of the context that restrains future possibilities. All of the young people and family members who participated in the study spoke of the future with a level of anxiety.

The young people who participated in the study all spoke of how distant they felt from their friends and peers by virtue of having the experience of psychosis and hospitalisation. In addition, the disruption to their lives generally occurred at a time when peer relationships were an essential aspect of their lives and they were in the latter years of their schooling.

Max, who had been hospitalised following a manic episode, started to contemplate his future after the mania began to subside.

> But then I got really depressed when the manic kicked off and really unhappy because I owed heaps of them money and stuff like that. And I’m like, wow, I’ve fucked up my life and I’ve quit Year 12 and what am I going to do for the rest of the year because I knew I was getting out soon. ... My confidence was shattered. I could no longer go out and sing to people for money and stuff. I was just shattered. ... The fact that I had all the time in the world and could do anything now so I was asking, ‘What do I do?’ I didn’t feel like I wanted to do anything and I was just so bored and I felt like I had screwed up my life. I kept thinking about wasting time and all the time I’d wasted and it wasn’t very pleasant. (Max, pp. 6-7)

Max’s loss of confidence was in part related to the loss of the liberating feeling of being manic and in part related to feeling out of step with his friends. His artistic nature had always been an important aspect of his being-in-the-world and in his relationships with others. The loss of the freedoms associated with mania was
experienced as a shock to his sense of self and had him longing for the ‘manic without the dangers of the manic.’ He was once again thrown into a world where he felt unsteady and anxious.

Because in hospital it was confined. There were people pressuring you. There were people imposing their viewpoint upon you and that gives you an immediate objective to retaliate and react to it. You know what I mean? If someone’s going to lock you in a room your immediate objective is to get out of the room and unlock the door. However, it felt to me that I was in an empty plane where any direction could have led me to some sort of oasis. I didn’t know which direction. I didn’t know which way to go. It feels like that same sort of freedom that you have if you were on a boat in the middle of the ocean. Sure you’re free, but where do you go when there’s horizon all around you?

(Max, pp. 6-7)

Not having a clear pathway to achieve his goals was very unsettling for Max. His being-in-the-world prior to experiencing mental illness had been one full of hope and plans for the future – the oasis which is now out of sight.

Penny revealed how devastated she was after receiving her diagnosis of bipolar disorder. She felt that her life as she knew it was over and it wasn’t until receiving encouragement from an unlikely source that she was able to reconnect with her hope for the future through her love of drawing.

I didn’t know what’s going to happen to me and then I was just like, my life is over and then I sort of felt defeated. (Penny, p. 16)

And there was this eye doctor I had to go to and he said his wife had bipolar
and he was like asking, ‘Are you doing anything in hospital?’ and ‘What do you want to do when you’re older?’ And then I was just like, ‘I’m not sure but I really want to go and illustrate my own book.’ And he’s just like, ‘You have some free time in hospital.’ And then I was just like a bit okay and thought, yeah. (Penny, p. 19)

It was this unexpected encouragement not to let go of aspects of herself that were so important to her sense of self prior to becoming ill and the support from her family that enabled her to believe that psychosis had not ‘consumed’ her life.

As mentioned in the last chapter, Sara was acutely aware of the potential impact that stigmatisation could have on her future and she actively made decisions to protect the potentialities of her future. She talked about the measures she took to avoid a collision between her two worlds, the one of academic and social achievement and the other inclusive of mental illness. Her determination to ensure that the stigma of mental illness would not influence her future achievements led her and her family to devise an alternative reason for her hospitalisation, one that was more acceptable to the Them world.

Even my family, they’ve told everyone they know, like my Mum and my sister, they tell everyone that I was in hospital with bronchitis. And so it’s something to keep secret (Sara, pp. 8-9).

Her decision to protect her future by keeping an element of her being secret from the majority of the people in her world resulted in her not being able to access the support of her peers during her hospitalisation.

The parents who participated in the study expressed concern about the impact the
experience of psychosis and the forced hospitalisation would have on their child’s future as well as their relationship with their child. While they all acknowledged the necessity for treatment, they also worried that the world of mental illness into which they had been thrown was one which is deeply stigmatised in the general community and had the potential to severely restrict their child’s future endeavours. Pam was worried that the experience of psychosis would limit the possibilities for her daughter’s future and struggled to find a balance between limiting the impact that the stigma would have and the need for her daughter to remain connected to her friends.

_I was scared that she would never be normal, never be able to do the things the other girls will. But then the nurse said that before the science was not so good, but now she can do anything – she can get married, she can have babies._ (Pam, p. 3)

After a particularly frightening night during which her daughter had been placed in an isolation room due to her loud and unrestrained behaviour, Pam wanted to bring some of her daughter’s friends in to distract and ground her, but was discouraged from doing so.

_They said she needed to calm down. I said that some of her friends wanted to visit her and this would be good. The doctor said that they shouldn’t come because when they go back to school some may gossip about her. If they love her they would not talk, but if they don’t love her they would talk bad and that wouldn’t be good for her._ (Pam, p. 3)

Uncertainty was a common feature of the parents’ experience. The existential anxiety that was concomitant to the fears the parents had for their children’s future left them unsteady and unsure about how they can best support their children. Their initial
instinct was to call on the support of family and friends, but when this was actively
discouraged by professionals, they were left to confront their fears for the future by
themselves.

While most of the nurses who participated in the study named the stigma associated
with mental illness as one of the key stressors for the young people who experienced
first episode psychosis, none overtly referred to the impact their illness experience
and hospitalisation would have on their future potentialities. The capacity to work or
attend school is an important outcome for those who have experienced psychosis and
yet research indicates that a low engagement with some form of occupational activity
is common place for this population six months after discharge from hospital (Singh,
et al., 2000). Some of the nurses in this study actively discouraged young people
from engaging in school work while others found ways to keep the young people
connected with their interests and strengths despite obvious difficulties with
concentration. Nicola described her attempts to engage a young person on the ward
in activities that would keep him connected with his interests prior to becoming
unwell.

_You try to keep them busy without overstimulating them. So we have a really
good art program that he was really good at, but his concentration span was
very short. He also liked music so we would play his sort of music... He always
wanted stuff on Wikipedia so we would print things off, but it’s hard because
we didn’t want to get caught up in his delusional beliefs. So things that were
music related, he liked to play guitar so we’d print off different songs. And
skateboarding, he really liked that so we got him researching that._ (Nicola, pp.
3-4)
Nicola’s actions were clearly aimed not only at alleviating boredom for this young man, but also to keep him connected to his sense of self that is not dominated by his illness. George refers to the centrality of the experience of safety in the now which impacts on the young person’s view of the future, and how this is expressed in the relationship that the nurse builds with the young person and family.

*It’s those personal interactions, I’ve said attachment sort of thing, but just to give them reassurance and to give them a feeling that they’re safe. ...we give them the expectation that things will go well and that can be as vague as anything so they feel better about the future.* (George, p. 3)

As identified by Jorm et al. (1997), there is a level of pessimism among mental health staff about the helpfulness of treatment and the future possibilities for those with mental illness. This was reflected in some of the comments from nurses participating in the study. While the general impact of stigmatisation in the community is acknowledged, that othering is reinforced by a lowering of hopes and expectations purely based on the experience of mental illness.

*I guess thinking back to the stigma, a lot of people have an idea of what schizophrenia if from the movies, they think of being psycho and being crazy. So I guess in a way that instils fear straight away because it’s unknown. ... I remember sitting with her parents for hours and hours, talking about the same thing over and over. And they would ask the same questions like, ‘Is she going to be like this forever? Is she going to be able to go on to university?’ ... So in a way, it’s about trying not to build their hopes up by saying that she will be fine. But she will be fine. She’s going to be able to live from day to day. She can have a happy life, but it probably won’t be the life that her parents’ dreamed*
for her and hoped for her. (Anne, p. 13)

The time Anne spent with these parents was clearly meant to be supportive, however, the overall prediction for this young person’s future was very pessimistic, with the experience of mental illness taken to be the dominant contributor to her life. Anne was inadvertently reinforcing the fear that the stigma instils.

In this last section it is clear how entrenched practices and understandings may contribute to rather than reduce the impact of stigma on the young person. The tensions between safety and security are not well attended to leading to more rather than less isolation.

**Summary**

In this chapter I have explored the ways in which hardened and unconscious attitudes and beliefs are confronted and absorbed by the young person and family members. The young people not only have to manage the stigmatisation of others, they are first confronted by their self-stigmatisation. This challenges their sense of self and agency. However, it is clear that much of the isolation and separation is augmented and sustained by ideas of ‘best practice’ that require some re-thinking. Stigma is seen as impacting on the person’s future by all involved. What is to be done about it is not arrived at through a partnership in all cases.

The next chapter deals with how a phenomenological perspective on care provides a view into the being in the world of the young person experiencing hospitalisation due to a diagnosis of first episode psychosis. In this chapter, I outline what such a view illuminates about care and how the subjectivity of the young person who is hospitalised with first episode psychosis is witnessed.
Chapter 7: Witnessing: an Ethics of Concern

Introduction

In the last two chapters, the experience of hospitalisation for young people with first episode psychosis has been explored in relation to the challenge to their being-in-the-world and their relationship with others. The young people and their families are thrown into the world of mental illness, the institution of psychiatry and the foreign environment of the psychiatric ward. The experience of being labelled by others and being confronted with the self-stigmatisation which is embedded in their own socialisation leads to isolation and a limitation of future potentialities. The familiarity of everydayness has fallen away, but while the Being-in and Being-with has changed, neither of these modes of Being is primordial.

Being-in-the-world which is falling and disclosed, thrown and projecting, and for which its ownmost potentiality-for-Being is an issue, both in its Being alongside the ‘world’ and in its Being-with-others. (Heidegger, 1962, p. 225)

Dealing with non-human entities in the world is not primary and interacting with others secondary, nor is being-with others primary and being-in-the-world derived from it. As with understanding and state-of-mind or mood, both are equally involved in our discovery of the world and of ourselves. The attribute of Being that underpins or unites all other aspects of Being is Sorge or care.

For Heidegger the concept of care is fundamental to Being. Care ordinarily has two senses: an ethical sense as in ‘care or worry about...’ and a practical sense as in ‘I take care of...’ Heidegger’s meaning of care involves both of these, but is also more
fundamental than either. It is not an attitude such as wishing, willing or hoping. One cannot worry, take care, wish, will or hope without caring about it in advance. Care refers to that which matters or essentially concerns us as Beings. It is the concept that unifies the different aspects that make up our being. The concept of care brings together the possibility that is Being or its projections of what can be, the thrownness of Being or that which ties down its possibilities, and the fallenness of Being or that which binds it to the They-world. All of this matters or is fundamental to the Being of human beings and reflects what it means to be a person. It is because care underpins our Being-in-the-world and Being-with-others that we can speak of concern about things in the world and solicitude for other people (Inwood, 1997).

Solicitude inevitably implies a social directive or what Heidegger calls a ‘factual social arrangement’. Such a social directive is implicit in the practice of nursing (Walton, 1995).

In this chapter I will explore the concept of care as it relates to nursing, with the movement beyond mere observation to the concept of witnessing that embraces and provides space for what it is that matters to the young people and family members. This solicitude towards others involves taking an ethical stand, and reflects a fundamental obligation to be with others in a way that provides space for their sense of self and agency to be acknowledged.

**Care and Mental Health Nursing**

Care is a term that is very familiar in nursing. The term ‘nursing care’ refers to the processes and tasks that are involved in assisting individuals, families or communities so they may attain, maintain or recover optimal health or quality of life. The term is also used to refer to particular subdivisions within the nursing profession
such as coronary care nursing, intensive care nursing or neonatal care nursing.

Nursing process has historically been seen as a way of thinking about nursing care, of providing “…a rational, scientifically based framework…” for nursing care and a method of establishing standards for nursing care (Phipps, Long & Wood, 1979, p. 87). It is my intention here, not to explicate nursing care as a significant concept\textsuperscript{14}, but rather to look at how mental health nursing care is spoken about as it relates to young people’s experience of hospitalisation.

The nurses who participated in this study all reflected on the nature of care in psychiatric or mental health nursing, particularly in relation to the care of young people experiencing their first episode of psychosis. For most, the building of a relationship that involved trust was fundamental to their nursing care. George, a Registered Mental Health Nurse with 14 years experience, described his ‘multi-person system’ approach which he uses to ensure that both the young person and family members are the focus of the new relationship.

\begin{quote}
I know in all our psychiatric mental health talk, we talk about dealing with the family as a whole but whose name appears on the case notes? The kids name. The kid is the ‘sick one’. So I will talk to them together [young person and parents] and then I’ll take the kid into the pills room just so I can talk to the kid alone because sometimes the family are so busy telling me about what’s happening ... the kid doesn’t get a look in. ... At the same time I’m aware that the parents are going to feel like, ‘Oh they took our kid away and they’re diminishing us.’ ... Sometimes I’ll take mum or dad aside so I can talk without the kid. This multi-person system can break up in lots of different ways and
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\textsuperscript{14} Many authors such as Benner & Wrubel (1989), Benner (2009), Nelson (2000), Nelson & Gordon (2006), Watson (1985) and Wynn (2002) have written extensively about care both generally and in specific fields of nursing.
Patrick reflected specifically on building a relationship with the young person in a holistic way and the importance of rapport in his nursing care.

>You know they talk about this concept of holistic care, you know this belief that you understand everything from every possible angle. I think when you talk about holistic, it’s a holistic understanding about, not only the episode that they’re in, but more importantly all the things that they’ve got up to in the past, what their likes and dislikes are, so you can understand them as a person, not just as a person with psychosis. ... I give them lots of encouragement when they’re managing things well, but when I need to step in and take control of the situation, it’s not just because they’re psychotic and their judgement’s poor, but because they’re kids as well, and when kids are frightened, sometimes adults need to find a way to get involved. Until they start to recover, and then in the recovery process you start to empower them a little bit more. It’s a step by step process I think. (Patrick, p. 3)

Patrick’s concept of nursing care is relational and privileges the young person’s being that preceded the illness experience. He demonstrates solicitude for the young people that is inclusive of, but does not take over their own agency.

Nicola, who has been a Registered Mental Health Nurse for three years, struggled with the different perspective on nursing care she experienced since starting work on the psychiatric ward.

>You feel like you’re being quite cruel. Like the whole sense of caring for someone who is psychotic is so different because you’re often limit setting or
you’re trying to contain them. So sometimes you actually feel like you’re not nurturing in the old way. ... Coming to this ward where your nurturing is completely different. Like your patient still comes first but it may be completely different to what I’ve ever done before. Medicating freely and trying to accept that’s alright. And restraining someone and putting them in seclusion is sometimes the best thing for that person to keep them safe. But that also is very different from anything I’ve ever been taught. (Nicola, pp. 1-2)

The primacy of nurturing and the provision of choices that were central to Nicola’s understanding of nursing care were challenged when working in the psychiatric ward and were replaced by pharmacological interventions and behaviour management strategies, with the twinned issues of risk and safety dominating.

The nurses all referred to their role in the administration of medication as a key aspect of the care they provided to young people with first episode psychosis. Some, like Patrick, linked this with the relationship they had developed with the young person, emphasising the importance of trust and rapport.

And the people [nurses] who tend to do the rapport stuff really well are the ones that don’t have many problems with giving medication to the kids, even when they’re paranoid. So when it comes to actually giving kids a PRN and they’re feeling overwhelmed, it’s much easier you know to discuss it and say, ‘This is what we’re going to expect from the medication.’ Whereas, I’ve watched other staff who don’t have the rapport try to give PRN and just say, ‘Here, you need to take it now’, then the young people tend to get quite startled and overwhelmed. And the whole developmental stage of being an older adolescent starts to come to the fore, you know. ‘I need to defend myself and
you adults can’t tell me what to do!’ (Patrick, p. 3)

Other nurses linked their role in the administration of medication with the management of risk, even when recognising this was not an optimal outcome. The use of a ‘safe room’ or ‘seclusion room’ was commonly linked to the administration of p.r.n. medication at times when the young people’s behaviour was a risk to themselves or others. Anne described the management of a young woman who was becoming increasingly distressed.

I guess as a team we assessed the situation because we had other young people on the ward and she was beginning to distress some of the other young people. So two of us grabbed her hands and she went quite willingly to the seclusion room. We gave her some IM medication to calm her down. There’s a mattress on the floor in the seclusion room and she lay down on the mattress and she burst into tears and was crying. She cried for a long time … but it wasn’t really crying. It was past the crying stage like a little child’s cry when there aren’t any more tears but if they don’t whinge they don’t get a reaction. … We like to assess the situation and once they’ve calmed down we actually unlock the door so they can come out when they’re ready, which she did and she walked to her room … and climbed into bed. And she slept for quite a while. The medication kicked in quite quickly. (Anne, p. 6)

The task driven nature of nursing care as described by Anne allowed no space for any other understanding of the situation to emerge. The lack of emotional engagement in a highly distressing situation for the young woman and her parents was demonstrated in the matter-of-fact and simplistic manner in which the incident was described. Through the use of protocols or policies, Anne is dealing with the
emotional distress of the young person in a detached and depersonalised manner. Her dismissiveness of the young person’s distress was an act of othering, creating distance in order to avoid being contaminated by what Goffman (1963) called the spoiled identity.

Recognising the motivations behind a young person’s behaviour, despite the fact that they may not be based in reality, and keeping the relationship with the young person central to any decisions about nursing care was an important aspect of Nicola’s approach. She acknowledged that this young person’s being-in-the-world involved ideas that were delusional but was also able to recognise the qualities that were key to his sense of self.

*He got restrained in a fairly unsafe way with three people instead of five and two staff got assaulted. He felt quite bad about doing that, but he thought he was doing the right thing, he was protecting himself. He was put in seclusion and given more medication. He got accuphased, so it was not a good outcome at all. He might have needed some midaz [midazolam], but he might not have needed accuphase. And then you lose all that trust because you are, according to him, trying to give him cancer so why would he trust you.* (Nicola, p. 5)

Nicola recognises that this young person’s beliefs, as distorted as they were, formed part of his current apprehension and it is the nurses’ responsibility not only to provide care in the least restrictive environment, but to do so with care that acknowledged his thrownness as being real for him. In privileging a relationship based on respect and trust over the language of restraint, she not only demonstrates

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15 See Glossary
16 See Glossary
the solicitude that underpins her nursing care, but also illustrates her commitment to physical and psychological safety in the ward.

Providing information to the young people experiencing psychosis and family members was seen as both an important aspect of providing care and a dilemma for nurses. Psychiatric hospitalisation of a young person is a time of crisis for any family and usually follows a period of escalating concerns about the welfare of the young person. People who have had a psychotic experience need to process and understand it, and if they don’t receive enough or any information to help them, this compounds the confusion and incoherence that the psychotic experience causes. Receiving clear and consistent information that is connected to their experiences can reduce feelings of disappointment and worthlessness (Kilkku et al., 2003). The nurses all acknowledged the importance of providing information to parents, but only one nurse talked overtly about providing information to the young people experiencing psychosis. The issue of consent to share information was raised as a barrier to providing information with family members, and the lack of a clear diagnosis on first presentation can lead to confusion.

*Sometimes little [information] is best, especially on first presentation of psychosis when you’re not sure whether it’s substance induced or organic. You get incredibly an incredibly anxious family and if you give them too much information they just can’t cope with it. But it’s also trying to make sure that they feel like they have a sense of control. The information generally gets so tricky because if they’re under 16 then you can pretty much give them any information, but if they’re over 16 we technically have to have the young person’s permission. ... I give a very basic overview of what being psychotic is
Patrick spoke overtly about helping the young people to understand their illness by identifying and discussing the specific ways in which it is impacting on their life. This approach privileges the experience of the young person and implies a focus on improving health and future potentialities.

_Orientating them to the fact that they are unwell is a very difficult thing for them to accept. That’s the first thing. I think insight oriented practice is important, providing them with the information and support they need to understand what’s happening for them. If they can accept in some way that they’re struggling or they’re finding things challenging or difficult because of their functional psychosis. ... If they’re actually able to gain some insight into what’s actually going on for them, then you would hope and feel that when they notice their symptoms becoming too much that they’re actually able to come and request support and medication._ (Patrick, p. 12)

The increased regulation and documentation of practice was identified by the nurses as a barrier to positive relationships with young people and families that have changed the nature of mental health nursing practice over time. Regulatory practices are those that are set by registration authorities and organisational policy. They also refer to the restrictions to the freedom of clients that are forced through the _Mental Health Act_. Observations are usually thought of in terms of what is reported to contribute to safety and risk. A focus on mere observation and not other interventions such as those that Patrick is referring to above has meant a reduction in time for interventions that provide information and give hope.

The other barrier to the delivery of optimal nursing care in psychiatric wards that was
identified by some nurses was the significant reduction in the length of stay. Historically, it was commonplace for young people with serious mental illnesses such as psychosis to be hospitalised for many months if not years (Scharer, 2002). Since the 1990s there has been a focus on the reduction of hospital bed days and an increase in day programs and community care. This has had a significant impact on the nature of nursing care in inpatient facilities. The young people involved in this study were hospitalised for between 2 and 6 weeks, with the average length of stay being 3.8 weeks. The changing nature of the health system has resulted in the focus being on hospital avoidance and limiting hospital stays. Danny refers to this as the ‘fast food service’ and questions whether the best service is being provided to young people experiencing psychosis.

The changing orientation of a lot of organisations these days is this – I referred to it earlier, like fast food service, you know, in and out. For people with serious or chronic conditions that doesn’t always work. (Danny, p. 5)

Patrick also refers to the brief nature of hospitalisation for young people with psychosis and the impact this has on the nature of the relationship between the young person and the nurse.

The way things have worked in the profession, it’s almost like being a robot. In some ways, you know, we do the quick sort of McDonalds treatment to get them quickly treated, make sure they’re not acutely psychotic anymore, discharge them out and ... hope we’re able to give them relatively good community care. ... I think if you don’t have time to build rapport and you’re just getting thrown a lot of medications all the time, and the kids aren’t actually understanding what the medications are for, they feel like guinea pigs and we’re trying lots of
different medications until we find the right one that works. (Patrick, p. 10)

With the emphasis being on finding the right medication, maintaining a focus on the key nature of the relationship between the nurse and the young person is lost. With the shorter length of stay, nurses become more reliant on procedural and regulatory processes which can be experienced as robotic, and the dynamic and potentially powerfully nurse-patient relationship became diluted.

Observation

One of nurses’ main roles in mental health inpatient settings is observational. Nurses are asked to assess the client’s mental state by observing their interactions with others, their ability to present themselves in socially accepted ways, their ability to understand and articulate what is happening to them, and their acceptance of treatment processes including hospitalisation. These observations take place during one-to-one interviews, when the client is undertaking daily activities, during visits with family and friends, and when the client is interacting with staff and other clients.

Nurses are also asked to observe the client’s behaviour for a reduction of positive symptoms of psychosis, which would indicate the effectiveness of pharmacological treatment. The unspoken tenet here is that the assessment made by the expert (in this case, the nurses) fully describes the experiences these young people have of the illness and treatment. The nurses’ observations are seen as having more accuracy and importance than those of the client or family because the nurses have knowledge of the disease and treatment process. In addition, these observations take place in an environment which is familiar to and, in part, constructed and controlled by staff, but which is unfamiliar, confronting and often confusing to clients and their families.
Nurses’ understanding of their observational role in this study was linked with their concerns with the policy-driven nature of their practice.

*When I ask nurses what’s different now, they often say, ‘I’ve got to make sure I tick this box, ... fill in the detention register, to make sure if this person absconds while they’re under the Mental Health Act that we’ve sighted them every 15 minutes or every 5 minutes. And I’m thinking, that’s all well and good, but what needs to happen is to allow that nurse to connect with that patient, and actually understand and have a rapport with them, so that patient knows that for me to be safe, I need to be in this particular environment. ... These days I think the patients will probably see it as, ‘I just want to leave this place because Jane over there behind the nursing desk is more interested in signing off on that piece of paper than actually worrying about me and how I’m feeling about where things are up to.’* (Patrick, p. 7)

The primacy of the relationship between the nurse and the young person is evident in Patrick’s comments and this appears to be lost in the policy-driven approach to nursing observation.

The nurses’ task of observation was also noted by the young participants, but described with a very different emphasis. Sara described her experience of being observed:

*Then there was this other nurse. She was okay I guess. I didn’t personally like her at all. I didn’t trust her. She walked around with a clip board all the time and just kept on looking at you, trying to scrutinise you or something. ... Yeah well, mainly she was just watching you in the TV room or I’d be talking to [another patient] or something like that, she’d be there and you wouldn’t even...*
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know that she was there. She’d sneak behind the door and listen in and stuff. ...

It just made me feel angry, like I was violated or something. Yeah [pause, then
tone lowered], I felt it was sad I guess. (Sara, pp. 4-5)

This experience of being observed does not convey a sense of solicitude, but rather
creates distance between the young person and the nurse.

**Witnessing**

Witnessing is a concept that has a strong basis in legal settings where the action of
giving testimony is privileged. However, as a counter to the process being reported
above, witnessing has two very distinct aspects or definitions. In legalistic terms,
witnessing is seen as the accurate eye-witness to historical facts at a given time.
However it is also seen as *bearing witness* to a truth about humanity that transcends
the facts.

... witnessing has both the juridical connotations of seeing with one’s own eyes
and the religious or now political connotations of testifying to that which
cannot be seen, or *bearing witness* (Oliver, 2004, p. 81, original emphasis).

Contemporary debates around the social struggles of marginalised people have
focussed on their fight for recognition, either as individuals, groups or cultures.
Charles Taylor (1994), in his discussion about multiculturalism and justice, centres
on the notion of recognition as the target for the social struggles of those who are
marginalised due to cultural difference. Oliver, a philosopher in the feminist and
phenomenology traditions, argues that this position is taken from that of the
dominant culture and reflects the othering of difference, reinforcing the power
differential that exists between the dominant culture and marginalised groups within
it. If recognition is seen as being granted by those in the dominant group, it repeats
the dynamic of privilege and power, thereby returning us to what Oliver calls the “hierarchy of domination”. By objectifying the other, the dominant culture denies the subjectivity of the other, thereby denying them a voice or a right to be heard.

The challenge is to step away from the dualism of self and other, and to create a space from which marginalised groups can speak. Witnessing, as described by Oliver, moves beyond the recognition of that which is privileged by the dominant culture, and sees the other not only as different, but gives those that are marginalised a space from which their agency is made evident. It acknowledges the invisible, “...what our eyes cannot witness...” (Oliver, 2001, p. 210). She asks:

How can we conceive of the tension between social and historical context with its differential power relations on the one hand and what makes us as beings who mean on the other? (Oliver, 2004, p. 81)

So how can we recognise that which is influenced by power attributed in social and historical circumstances as opposed to that which reflects the essence of who we are and the meaning we give to that. Whereas testimony is usually a spoken or written account of something one has experienced, witnessing speaks to the subjectivity and agency of the other. The potential of witnessing is not simply to provide testimony of another’s experience at a given time in a visual way, but to be a companion and co-being that does not rely on immediacy or closeness.

Subjectivity refers to one’s sense of self and our own agency. It is relational in that our sense of what is important, indeed our sense of meaning itself, emerges through our relationship with others. Our sense of our own agency comes from our internalised relationship with others, empowering us to act. However, if we are part of a marginalised group as people with mental illness are, our internalised
relationship with others may reinforce our sense of powerlessness and the limitations of our own agency. Our sense of self stems from the ability to address ourselves to others as well as respond to others. Oliver claims that subjectivity is developed and sustained by the ability to address others and be addressed by others, and the ability to respond to others and oneself.

If the possibility of address is undermined or annhilated, then subjectivity is also undermined or annhilated. To conceive of oneself as a subject is to have the ability to address oneself to another, real or imaginary, actual or potential (Oliver, 2004, p. 84).

As subjectivity is relational, the fundamental obligation that underpins witnessing is “... to respond to others in ways that open up rather than close off their response” (Oliver, 2004, p. 86). Witnessing requires us to take an ethical stand, to take responsibility for the effects of our actions on others as they are demonstrated through their responses. Part of the therapeutic task when working with those who have been marginalised or oppressed is to reconstruct the addressability that makes witnessing subjectivity possible (Oliver, 2004).

The family members involved in the study very clearly articulated their witnessing of their child’s or sibling’s experience both of their first episode of psychosis and their experience of hospitalisation. Pam bore witness to her daughter Penny’s escalating distress as the symptoms of psychosis became unbearable and debilitating. She sought to decrease the isolation that she witnessed as part of the hospitalisation by asking if her friends could visit. When this was denied, she invited her friends and cousins to visit when Penny first had day leave, providing a movie and food to help Penny reconnect to her pre-illness social life.
Julie, while grateful for the support she experienced while her son was in hospital, recognised the impact that boredom and isolation were having on his hospital experience and asked about the potential for peer support.

*He just got very bored, very bored. I know that they went out and got some schooling once a day when they were feeling better, but he didn’t go to that the first time [he was in hospital]. I don’t know whether they could have some teenagers on some kind of work experience who could perhaps visit the hospital and spend some time and talk to them if they wanted to talk about their experiences. Just play some games with them or something.* (Julie, p. 8)

Sue also referred to the impact that the lack of stimulation had on her son Max’s experience of hospitalisation and recognised his response as one of rebellion.

*He’d keep saying there’s not anything to do. He decorated the whole wall of the art section with paper and he used to draw intricate maps and drawings and stories, and they were running out of things to, mentally I suppose, keep him occupied, yeah. ... One time when I came he’d been put in the quiet room because they said that, he’s not aggressive, like he wouldn’t hurt anybody, he would get up their noses though. And one day he threatened to sing all night. Sing is not the right word though [laughter]! So he wasn’t aggressive to other patients or staff, but he was very clever at getting up their nose.* (Sue, pp. 6-7)

Sue’s validation of Max’s right to rebel despite his manic state culminated in her support for his challenge to his detention under the *Mental Health Act* by engaging a lawyer.

Kaye very clearly articulated her sister’s experience of illness and hospitalisation.
Emotional and very terrifying and I knew she was very emotional about the whole situation and wondered, why her, why did she have it. And I just think her life is very different now that she has it. Socially she doesn’t go out as much as before, not a major difference, just a little difference. She’s more artistic now, she’s more into expressing herself through drawing, painting, writing, things like that. (Kaye, p. 5)

She acknowledged that her sister’s experience of hospitalisation was positive when she was most unwell because it provided safety and gentle support, but when she started to get better, the isolation and lack of social activities became evident.

All of the nurses interviewed in this study had difficulty focussing on this concept of witnessing the young people’s experience. Their initial response was to describe what they have seen from the safety of the constructs that guide their nursing care.

With additional questioning, some were able to focus on the experience of the young person and then reflect on what that meant for their own practice. Responses ranged from an acknowledgement that they had not considered the experience of the young person:

I’m talking about what they experience but I haven’t got a bloody clue what they experience! So I know that the stuff that we do that’s supposed to affect their experience, but there is all that pre-existing stuff in their lives. (George, p. 10)

None of us can know what the other experiences, but how the nurses witness the young people’s world through solicitude can influence their relationship with them and their reflection on their own practice.
Alternatively, another nurse was able to connect with the experience of the young person and recognise the impact it has on his nursing practice.

*It was frightening in the sense that the young person felt no control over what was happening in his life. And it was heart wrenching, watching him cry and be distressed, at the same time asking me questions like “Why me?” when he had his moments of lucidity. ... It was an awful experience, but one that you had to sit and hold and contain, and attempt to manage it as you try and nurse them through it.* (Patrick, p. 1)

In moving beyond recognition of the young people’s experience, some nurses described the process in which they would develop their relationship with the young person aside from the psychotic experience. In this way, the nurse is creating a space for the young person to express themself in a way that is not dominated by the illness experience:

*I spend a lot of time just understanding how it is, and how you should support him, you can ask those questions fairly openly, and constructively, and, that was probably the definer, I think that made it a little bit easier, to support him through it, no doubt. ... but, I think it was the general stuff about, you know, understanding it from his world, in the sense of you know, what he was like before he became unwell, what was important to him, so when he was in a fairly distressed and unsettled state, we could actually bring him back to the reality of what life was like beforehand.* (Patrick, p. 2)

Both the psychotic illness and its treatment have an impact on the way one is in the world. The focus of our Being-in-the-world is shown through the situations and the things that matter in our lives. The illness and treatment of psychosis are part of the
past, present and future of these young people who have experienced it, and yet they sit alongside of but do not take over other ambitions, relationships or other life issues.

The disturbing sensory experiences that are symptoms of psychotic illness are initially not challenged by the young people who are becoming unwell. The nurses involved in the study unanimously spoke of this challenge to the taken-for-granted as a “lack of insight” that young people had into their illness and then reflected on how this influenced their nursing care, some in the context of relationship and nurturing and others in the context of managing risk.

In everyday life we do not challenge our sensory experiences. It is also commonplace to misapprehend our sensory experiences and to believe our misapprehensions. It is only when these misapprehensions impede our everyday functioning that we question them. The young people experiencing first episode psychosis are confronted with the apprehensions of the medical world that conflict with their own explanations of their sensory experiences. The nurses share this capacity to misapprehend with the young people. However, the nurses’ use of the term ‘lack of insight’ when referring to the challenge to the taken-for-granted implicitly denies that they too behave in this non-reflective way on a day to day basis. It points to a significant philosophical difference between the medical perspective and the experience of the young people. The tension that lies between these different philosophical orientations towards sensory experience is neither acknowledged nor addressed by the nurses involved in the study. The young people’s apprehensions of the alternate sensory world into which they are thrown were neither witnessed nor validated.

Moreover, the use of the word ‘insight’ in psychiatric terms refers to the ability to
recognise one’s own mental illness and how the illness affects their interactions in the world. As a counter to this fixed view of ‘insight’, Markov and Berrios (1992) offer a view that symptomatology are best not considered isolated effects, but rather are a continuum of thinking and feeling. In practice, I believe the term ‘lack of insight’ reinforces the stigma attached to mental illness and limits other possible understandings of the experience. The alternative, to be insightful, a term that is situated in the person, is to be grounded in knowing that is not readily taken into account. This again highlights the tension between the application of medical symptomatology and the philosophical orientation towards the person. Witnessing attests to and validates the young people’s experience of alternate sensory occurrences, enabling them to understand and engage in ways to manage them.

Patrick was the only nurse involved in the study who obliquely referred to the relational nature of what he termed ‘insight oriented processes’. He describes the way in which he uses his relationship with the young person and family to assist them to understand what is happening through experience. He recognises the importance, developmentally, of providing or enabling these young people to maintain control in their lives through partnership rather than imposing control on them.

*In certain scenarios I see stages that kids can have it [control]. This is certainly not something that I want to be doing. I don’t want to be taking control of you, and, you know, we want you to be in control of your life. And these are the things that we expect that you’re able to do to feel like we don’t need to be intruding all the time. It might be that you need to shower every day, or look after yourself, or when things are getting out of control, then you can*
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*acknowledge that things are getting out of control as well and you might need to have a bit of quiet time somewhere. ... And you know, they can control what’s going on if you arm them with the right insight oriented processes to allow that to happen.* (Patrick, pp. 11-12)

The policies that guide nursing practice in this area use language that reflects the need for intervention and control. The concept of ‘risk’ is a major influencing factor in guiding practice and “continuous one-to-one monitoring techniques” are used to assure safety when risk levels are considered to be high. While it is recognised that what is called ‘specialling’ or continuous observation is the most restrictive level of patient observation, in the principles and practices of this monitoring technique there is no reference at all to the role of the nurse being anything other than custodian.

There are clear instructions about how far from the patient the nurse must be, how observations of the patient’s behaviour and mental status must be recorded in the clinical notes every hour, and how the nurse must respond if the patient is attempting to harm themselves or leave the unit.

All of the nurses interviewed commented on the regulatory nature of nursing practice within the ward, with one likening it to the “McDonald’s or drive through treatment”. There has been a strong emphasis on reducing the length of stay for young people in psychiatric inpatient units and at the same time a corresponding push towards managing risk. The need to decrease the length of stay is administratively and economically driven with the focus being on speed rather than therapeutic intent. Nonetheless, the social directive implicit in the practice of nursing (Walton, 1995) and the ethical imperative implicit in the concept of witnessing impel us to take responsibility for the impact of our clinical practice on clients. The dilemma for
nurses lies in the ability to address the tension between regulatory nursing practice and the social and ethical imperatives implied in nursing.

Solicitude can take one of two forms. On one hand it may be seen as ‘leaping in’ for the other, intervening, taking control. The nurses interviewed spoke of times when they had to intervene and take control, but from very different perspectives and reflecting varied understandings of the experience of the young person. Anne, when describing a young person’s response to the confusion and fear of not knowing in an environment that she considered as hostile, very quickly slipped in to managing risk.

*She was yelling at the top of her lungs, to the point where we were required to use the seclusion room because she was becoming quite aggressive, so we popped her in the seclusion room.* (Anne, p. 5)

On the other hand, solicitude may be seen as ‘leaping ahead’ of the other in their potentiality-for-Being (see Patrick’s comments on p. 179-180). This kind of solicitude is concerned about helping the other achieve their potential, to become what they are able to be.

This kind of solicitude pertains essentially to authentic care – that is, to the existence of the Other, not to a “what” with which he is concerned; it helps the Other to become transparent to himself in his care and become free for it.

(Heidegger, 1962, p. 159)

Aspects of mental health nursing that reflect this form of solicitude include advocacy and the use of relationship to assist the young person to achieve their potential. Heidegger points out that being concerned about things that matter to us is a condition of human existence, and to be able to demonstrate solicitude to others
requires a genuine Being-with-others that contrasts with the indifference and unsociability common to everyday, dominant modes of Being-with. As Munhall (1990) says, “We share the world with other people, not merely with organisms whose human status is in doubt” (p. 116). For nurses to demonstrate care and solicitude for young people experiencing first episode psychosis, they need to be able to understand these young people and their world, what the world looks like to them and how they see themselves in it. In bearing witness to the experience and understanding of these young people, nurses create a space from which the young people can speak and through which their agency is acknowledged and validated. Only from such a space is it possible for them to bring together the young people’s apprehensions of their illness and hospitalisation with their own clinical understandings of psychotic illness and treatment.

**Summary**

In this chapter I have explored witnessing as a concept that enables us to understand the phenomenon of hospitalisation for young people with first episode psychosis. The notion of care holds and integrates the aspects of Being: its possibilities, its thrownness, and its binding into the They world. Care also implicitly points ahead to the temporal nature of Being. Care is mutually interdependent to the significance of the world. It is only if the nature of Being is care can we dwell in a significant world, and it is only if the world is significant can our Being care (Inwood, 1997).

This view of care contrasts with the ideas of custodial or observational care as driven by protocols. The family members were not so positioned and more likely to witness the experience of the young people however with less resources to overcome the difficulties each person experiences. The relational nature of subjectivity is such that
the young people’s sense of their own agency is developed in reflection on their relationship with others. The restrictions on visitors not only contributes to the stigma associated with mental illness and the limitation of future possibilities, it also reduces the space from which these young people can be heard and thereby re-connect with their own agency. There is a tension between the technical practices of nursing observation as disclosed in policies and described by nurses, and being able to witness with solicitude to the meaning of the experience of hospitalisation for young people.

In the final chapter in the final findings chapter of this thesis, I move to problematise the aspects of time and space as these intersect in the experience of hospitalisation for young people. The implications this has for their experience will also be addressed in the next chapter.
Chapter 8: Connectedness in Time and Space

Introduction

Young people who have been hospitalised following the first episode of psychosis find themselves thrown into the marginalised world of mental illness and institutionalised psychiatry. This is a world in which stigmatisation has a significant impact on their sense of self and future potentialities. In the world of mental illness, the dualism of self and other is so strong that the subjectivity of the young people, their sense of self and their agency, is overwhelmed by the dominant culture and apprehensions of psychiatry. The relationality of subjectivity lies in the fact that it is through our ability to address ourselves and others and respond to ourselves and others that we develop a sense of our own agency. In the last chapter, the concept of witnessing with solicitude was explored as an ethical stand aimed at reconstructing the addressability that makes witnessing subjectivity possible. For nurses it means moving beyond observation to create a space from which the young people and family members can speak. This is the ethical or social directive that nurses face in their relationship with young people experiencing first episode psychosis.

Heidegger’s notion of care has three characteristics: it is ahead of itself in terms of its awareness of possibilities; it is already in the world because of the past; and it is alongside others either with solicitude for others or concern for entities in the present. Care signals what matters to us as human beings that speaks to essential nature of our Being. We could not demonstrate concern and solicitude if our world was not significant, and it is only because care is the essence of our Being that we can live in a significant world (Inwood, 1997). With care bringing together the past,
future possibilities and the present, it implicitly points ahead to the temporal nature of Being.

Just as all speaking about the world there lies Dasein’s speaking out itself, about itself, so all concernful dealing is a concern for the Being of Dasein.

(Heidegger, 1992, p. 9, original emphasis)

The concernful dealings to which Heidegger refers occur in the world and with others, in time and space. Heidegger does not treat time as some sort of metaphysical formulation, as an entity or substance. Rather, he asks: What does it mean to be in time? While Heidegger places more emphasis on time over space, he is also interested in Being in the world and spatial access.

In this chapter the way in which time and space are experienced by young people who have been hospitalised following the first episode of psychosis is explored. In phenomenological terms, time and space are concepts that are interdependent and link to the experiential and relational nature of Being, therefore it would not be possible to talk about time without considering space. Some of the issues that have been discussed in the last three chapters will be revisited in this chapter and considered in the context of temporality and spatiality.

**Temporality**

Heidegger describes four different but connected conceptualisations of time. The first is primordial or authentic temporality, the temporality of Being-towards-death and resoluteness. The second is the temporality of the everyday Being, of the inauthentic self that is immersed in the They-world. The third is world-time or the public time when we are with others. And finally he describes ordinary time is seen as an endless recurrence of the present moment. Each of the last three is derived from its
predecessor. In starting with the most complex phenomenon, Heidegger emphasises the uniqueness of human beings in striving to attain order and significance in the world (Inwood, 1997).

The authentic self is not consumed by the present or the immediate past and future. The authentic self looks ahead towards death and to the historical past before deciding what to do in the present (Inwood, 1997). Tradition and historicity have significance for the authentic self, as do future possibilities. “Dasein is not confined in its awareness to the present moment. It runs ahead into the future and reaches back into the past” (Inwood, 1997, p. 68).

As the Being of human beings is temporal, this speaks to the temporality of the world that has significance. In Being through care, we are open to and open up the world. It is through our relationship with the world and with others in the world that we are defined. Our experience of Being occurs with reference to past, present and future, but time is suspended in space, and it is in this space that we become conscious of Being. “In its countless alveoli space contains compressed time. That is what space is for” (Bachelard, 1969, p. 9).

**The Hospital Space: A Place of Temporal Refuge or Safety?**

The issue of safety was raised by all participants in the study, but from very different perspectives. The young people’s experience prior to coming to hospital had a significant impact on their perceptions of the psychiatric ward on arrival. Similarly, the family members’ experience of witnessing their child’s deteriorating mental state was distressing and raised fears not only for their physical safety, but also for their psychological wellbeing. The nurses speak about safety within the present context of the ward from the perspective of managing risk and maintaining physical safety.
The concept of asylum in mental health is of longstanding origin, first seen in the asylum movement in the 18\textsuperscript{th} century. The institutions that developed quickly became associated with interminable suffering after an earlier more halcyon phase that did not continue past its first promoters including Chiurugi in Italy, Pinel in Paris, and the Tukes who founded the Retreat in York (Porter, 1987). The practices of the asylum institution came to conceal the suffering and needs of the mentally ill person. In institutions, it is the needs of the institutional organisation that are recognised, while the needs of the ill person become invisible (Colucci et al., 2000). The concept of asylum being a sanctuary or a place of refuge and safety was lost.

While there have been examples of service development in the second half of the 20\textsuperscript{th} century such as the Trieste Mental Health Department that focus on restoring the rights of citizenship to those with mental illness in a community setting (Colucci et al., 2000), mainstream mental health services in Australia have struggled following the implementation of deinstitutionalisation to find the balance between the need for a place of asylum and refuge and care in the least restrictive environment.\textsuperscript{17}

To seek refuge is to find shelter or protection from danger or trouble. All of the young people who participated in the study had experienced frightening psychotic symptoms that were escalating out of control prior to hospitalisation and for most, this had been happening over many months. For Amy, who was traumatised by both the frightening hallucinations and the involvement of the police in bringing her to hospital, the fear, confusion and lack of control permeated her entire experience of hospitalisation. Being in a psychiatric ward was not a safe place for her, either emotionally or physically.

\textit{It was so frightening! We weren’t allowed to do anything in there. Well, that’s

\textsuperscript{17} See Chapter 2 for further discussion about the history of the concept of asylum in mental health.
my experience and I want to share it! I know I’ll never be able to look at the hospital in the same way again. (Amy, p. 2)

Even the experience of basic medical procedures such as blood taking, which she had never experienced before, was linked with the lack of control associated with her involuntary status.

I’d never had blood taken before. I’d never had to.

Q. So how was that explained to you?

They didn’t. They said you need to have this or you can’t leave. So I said, ‘Here, I’ll take it. I’ll do whatever I have to do to get out of here.’ And then they still wouldn’t let me leave. Then they said, ‘We have to take a CAT scan of your brain’ or some shit and then that would take until Monday. And then they detained me on Monday and wouldn’t let me out. They just kept me in. ... I didn’t get on with most of the staff, only about three nurses. Yeah, the rest, well they didn’t like me. I was too much of a smart arse for them, so they got pissed off and they detained me and then detained me again, and then undetained me and then detained me again! I had it about three times. (Amy, pp. 2-3)

Amy was trapped in a present over which she had no control and in which her past was not acknowledged or validated. Her relationship with a greater proportion of the staff was characterised by distrust and this persisted throughout the admission. During her interview for the study, the persistent anger and fear relating to her experiences in hospital were very evident. Amy described her understanding of what was happening to her as “I just felt very lost” (Interview, p. 8), but during her admission this understanding was not explored or validated. Not only were her
sensory apprehensions frightening and confusing, but she was being separated from her past and future, thereby denying her the ability to express her authentic sense of self and her agency.

For other young people the psychiatric ward to which they had been admitted was experienced both as a place of refuge and one of fear. Penny experienced both the safety of supportive relationships with the nurses and the fear associated with managing past experiences and future possibilities. Despite the “bumpy ride” to hospital and the frightening hallucinations, she found comfort in the small interactions with the staff that reminded her of home: the help in basic activities such as showering, being tucked into bed. The focus on the present initially helped her to become oriented in this foreign environment, but soon the demands of the past and the future needed to be addressed.

*I felt okay at first because like you’re always in the ward and you don’t need to answer any questions like about your absence and things, so I didn’t think about it a lot in the ward. And how am I going to tell my class mates? How am I going to tell my friends? ... I didn’t even think about what to say to those people who want answers. And what’s going to happen to me in the future, to my finishing school? ... We just talked about my medication then [preparing for discharge] ... After I’d had another relapse ... they talked about it and stuff but by that time it was a bit too late. (Penny, pp. 8-9)*

While the psychiatric ward was able to provide an experience of refuge and safety for some young people, for others the challenge to their own apprehensions about mental illness when confronted with other young people who they considered to be significantly more unwell and therefore more unpredictable than themselves, had
them feeling unsteady and anxious about their own safety in this unfamiliar environment.

_Never they put me in another part of the hospital ... whatever the mental part of the hospital is. They shoved me in there with a bunch of mental cases! And then I realised I was meant to listen and I couldn’t get out for 2 1/2 weeks. It’s a hell of a life in there! I didn’t know what to do._ (Amy, p. 1)

All of the young people involved in the study spoke about their experience of the seclusion or time out room, a room specifically designed to keep young people safe when their behaviour was deemed to be a risk to themselves or to others. Some young people experienced the use of this room directly while for others, the witnessing of others being placed in the room just as powerfully contributed to their fear and distrust. Max, for whom freedom of expression was a key aspect of his sense of self, regularly challenged ward processes and this resulted in his experience of the seclusion room.

_One of the times I just refused to go out, and oh yeah, I had the whole straight jacket thing – oh, it wasn’t really a straight jacket! I just thought I could escape right now and I just want to see how hard it really is, so I just kept pounding on the door for thirty minutes. And I got out! And wow, I’m out and I was in this other room for ages and they all noticed ... and then they came and grabbed me and pulled me back in. I tried it again about an hour later and then they got serious. They put me into this room and tranquilised my butt. It was kind of cool how I was instantly out. I was just knocked out and locked in that room. And I woke up the next morning and the door was open. I just wanted to get the experience so I could write about it later._ (Max, p. 9)
Max’s pragmatic description of his containment was immediately followed by a disclosure that he feared that his throat would be slit while he slept, demonstrating the conflicting and confusing experience of the ward as a refuge. Penny experienced ambivalence regarding her containment within the seclusion room.

Maybe the seclusion room could have an actual bed instead of a mat, yeah. I really like that room because there were clouds in there [on the walls] so that when I was unwell I could go there. It’s just like a room with four walls and clouds and there’s no bed.

Q. What was the room used for?

Like when you’re really out of control and you need to be shut away from the rest of the ward, it’s safe. I experienced that. ... All I remember was I was in seclusion and it was pitch black and a needle was stabbed in my bottom. I felt like, ‘What the hell!’ ... There was this door but you can’t see anything outside the window. ... I just didn’t like it because it was pitch black and I was trying to get out. ... It felt like a really long time before they finally opened the door.

(Penny, pp. 13-14)

Penny initially internalised the notion of being ‘out of control’ and the need for safety, and could even appreciate the potentially calming nature of the decoration on the walls of the seclusion room. However these decorations were not useful in the darkness, and the elongation of time was experienced in the absence of visual or relational cues. Neither the past nor the future is available to Penny. In philosophical terms, time cannot become long because it originally has no length. The fundamental phenomenon of time is the future. The question of ‘how much longer’ “... cling[s] precisely to that which is not yet past and ... [busies itself] with what may possibly
remain for me” (Heidegger, 1992, p. 14). After being thrown into the unfamiliar and frightening world of the psychiatric ward, Penny is then thrown into a world of containment that deprives her of any certainty about her future, with the now being an experience of prolonged fear.

For Amy, witnessing other young people reinforced the distrust and fear that dominated her experience of being in hospital. It was a reminder of the lack of safety she experienced prior to coming to hospital.

*It was pretty hard when there’s nobody there and you’re feeling lost the whole time. Yeah, it was scary. I thought I was going to get fucking jumped.*

*Q. Did you still feel that fear when you were in the ward?*

Yeah! There was a room strictly there and they could just throw you in and lock you in there. ... I knew a few people that were in there, and they drugged them up. You don’t see that part on the camera. I was scared as hell knowing that they could do that to me. They could just slap you in there and hurt you, then they would, right. They knew it was legal. ... I’m pretty sure that they [her parents] knew how scared I was. [Trembling] I cried all the time when I was in there. I’m pretty sure they did as well. (Amy, p. 9)

The nurses too spoke of restraint and seclusion in terms of reducing the risk of harm to the young person or to others. This sat within the context of the general level of coercion involved in the young person’s hospitalisation. Some nurses were able to reflect on the impact this had on their nursing practice while others were not. George reflected on the impact this coercion had on his ability to develop a trusting relationship with the young people.
[Name] is a kid that we’ve got now and he’s probably on Form 3 or Form 4\textsuperscript{18}, I can’t remember now, and he’s really shitty because he’s still in here, and ‘there’s nothing wrong with him’ and ‘we should let him go’ and all that. The whole concept of trust is irrelevant because he’s from a family where people have been murdered, people are in gaol, people steal each other’s Centrelink\textsuperscript{19} money and drugs, people bash each other up ... and who knows why. So the idea of the concept of trust is seeds falling on a barren ground or something like that. There’s no way that it can happen in the first place. And we are frankly quite coercive. Most of the kids, although they’re nominally voluntary, because their parents want them there [in hospital], the kids certainly don’t want to be there. ... We are coercive, in cahoots with their parents or sometimes the law. So we can do all the things we can do to appear to be trustworthy or to engender trust, but whether it’s going to work and whether there’s any background that it can grow on is a whole different question.

(George, p. 9)

George recognises that the level of coercion involved in the hospitalisation is one of the factors that impede the development of trust between the young person and the nurse, trust which he previously identified as a key aspect of both the young person and the family to feel safe in the space of the ward and positive about their future (see excerpt p. 110).

For some nurses the seclusion room was just another room in the space that is the psychiatric ward, to be used when the young person’s behaviour poses a risk to themselves or others. There are restraint and seclusion protocols to be followed and

\textsuperscript{18} Form 3 refers to the level of detention under the Mental Health Act. A Level 3 detention and treatment order expires in six months unless revoked earlier by the Guardianship Board.

\textsuperscript{19} Centrelink is the Commonwealth organisation responsible for welfare payments.
paperwork to be completed. The young person’s subjectivity is lost in the application of these protocols and safety becomes a one dimensional concept that occurs in the now. Anne’s description, cited on page 165, of what appears to be an extremely distressing situation for both the young person and her parents, leaves no space for the acknowledgement of this distress. She refers to the length of time the young person was in seclusion in clock-time, with no reference to the impact the experience would have on the young person’s sense of self.

_The episode probably, including the whole time she was in seclusion, about 40 minutes. Yeah, we don’t tend to keep them in seclusion for very long. We like to assess the situation and once they’ve calmed down we actually unlock the door so they can come out when they are ready._ (Anne, p. 6)

Anne refers to the amount of clock-time that the young person spent in seclusion as not ‘very long’. Indeed, in recent research regarding seclusion rates in adult mental health services, 7.4% of participants were secluded once or more during the first two weeks of their admission, and of these 53% were episodes of less than one shift and 38% continued from one shift to another (Bowers et al., 2011). While this data indicates that seclusion episodes are longer in adult mental health inpatient services, it reinforces the concept of seclusion as a uni-dimensional concept, relating only to physical safety, and time is identified only by clock-time.

In contrast to Anne’s policy-driven approach to safety, Nicola explored the complexities of a situation that may result in a young person being placed in seclusion. While she clearly had a good knowledge of the recommended procedures to manage situations where physical safety was threatened, the needs of the young person was central to her discussion about safe and unsafe nursing practices. The
acknowledgement not only of past trauma, but also of the trauma that is inherent in
the containment practices, influences her nursing practice. She saw it as her role to
advocate for a conscious reduction of restraint episodes for a young person who was
highly distressed and paranoid.

This boy was very unwell and he needed to have his regular depot injection.\textsuperscript{20}

But it was also quite clear that the dose of medication he was on wasn’t
holding him. He was going to need some accuphase because he was getting
more and more agitated. So I said, ‘Why can’t we give them both at once. It’s
going to be awful for him because he’s not going to take it willingly, so instead
of being restrained twice, let’s do it all in one hit.’ I had to push really hard.

They [other staff] wanted to leave the depot for another day. We are going to
need to have a relationship with this boy that’s going to last in the future. We
have to try and reduce the unpleasant stuff as much as we can. ... I think it
[advocacy] is part of our role because they [clients] are so unwell at that
stage, you have to try and keep them safe and ... that they get the best
treatment. (Nicola, p. 5)

Nicola’s concept of safety moves beyond the management of risk in the now, being
inclusive of the past and present, and sees safety as a relational issue. It recognises
that nursing practice in this context is more than a mere sequence of events, a series
of nows, and encourages a temporal and relational understanding of safety.

To find shelter or protection is an innate human desire in the face of danger or
trouble. But if that refuge is only inclusive of the present and ignores the past and
future possibilities, it runs the risk of presenting safety as purely physical in nature,

\textsuperscript{20} See Glossary
something that can only has significance for the now. The tradition, historicity and future potentialities that are challenged by the experience of first episode psychosis and hospitalisation must be acknowledged and validated for true refuge to be experienced.

[The] virtues of shelter are so simple, so deeply rooted in our unconscious that they may be recaptured through mere mention, rather than through minute description. Here the nuance bespeaks the colour. (Bachelard, 1969, p. 12)

In order for the nuances of safety as experienced by these young people and families to be witnessed, space in the relationship between young people, family members and nurses needs to be created to explore the trauma of becoming unwell, the fear related to forced containment, and their concerns for the future.

**Relational Space**

All of the participants in the study spoke about the space that is the psychiatric ward, in terms of the nature of this place, how the space was used and the relational dynamics within the space over time. The young people had a more nuanced understanding of the complexity of the space of the ward as they tried to determine how to engage with this foreign space into which they had been thrown. For some, there were subtle aspects of relational space that helped them to connect with comforting memories of home. Penny described the gentle care provided by a nurse at a time that was frightening and confusing.

_I just remember going into the ward and my cousin was there and I just didn’t know what was happening. ... And then I took a shower with my clothes on and the nurse said no, I needed to take my clothes off and she helped me, and that’s when I was all these stickers on my body and I started to cry. But the nurse_
said, ‘it’s OK, they’re just from the other hospital from the heart machine.’
And then she put me to bed, like tucked me in. I thought she was Mum. (Penny, p. 4)

Penny also related the experience of being in the space of the ward to that of being as a family, interacting around everyday activities such as cooking. Her experience of her relationships with staff was generally very positive, however, she found the individualistic relational style within the ward confusing.

I pretty much got it all [care from the nurses], but it’s just like the patients, we just all hang out together but not together. So maybe I would like some more group stuff like if we could cook something or, you know what I mean. ... It’s more about like a family. I know we’re not a family, but like a group thing. I mean, we’re staying here together, we might as well do things together, like cooking and stuff, yeah. (Penny, p. 11)

Penny raises the importance of relating with others through everyday activities, activities that are not dominated by the experience of psychotic illness but allow the expression of the young person’s sense of self. Heidegger emphasises that we are defined through our everyday experience in the world with others (Heidegger, 1962).

For other young people, the nature of the space that is the psychiatric ward reflected the unsteadiness and anxiety of being thrown into a foreign environment. The issue of physical safety and containment masked broader concerns of connection with others and the loss of freedom. When Max’s mania started to subside, there was a change in his relationship with the space that he inhabited, and the loss of his care free past and his concerns for his future became a key element of his experience.
You weren’t allowed to take some stuff in. It was kind of weird, after a while I’m just noticing things, like little things I realise [are] in place to stop people from hurting themselves. Like you can’t lock the toilet and all the utensils are plastic. It was weird. And sometimes I got a bit sad because I wanted to go outside and sing to people and everything. Just open the window and look down at people and I couldn’t be down there. What am I going to do now? (Max, p. 10)

Amy also noticed the security features in the ward, and the experience of containment and lack of control added to her anger and confusion.

Like I said, it was like a prison, a mini prison in a hospital. It didn’t feel like a hospital. It felt like a prison with double windows so then if you try to jump out the window, there’s another window stopping you. ... Yeah, I was there and they were stopping me from getting out. Three doors! And they had everything in there – TV, kitchen, bathroom, everything, just no fresh air.

Q. What would you see as a normal hospital? How would you describe that?

Where there’s lots of sick kids getting better. (Amy, p. 8)

The environment of the psychiatric ward challenged Amy’s understanding of what it is to be unwell, and contributed to a sense of hopelessness about the future and her capacity to return to a sense of self that is not dominated by illness.

Whose Time is in Focus?

For the young people who participated, the experience of emerging psychotic symptoms and hospitalisation was temporal in nature. The experience of becoming unwell and being hospitalised was not considered to be an isolated experience that
had meaning in and of itself. It was not seen as a series of separate events in their lives. Their experience was an integrated part of their whole life, past, present and future, and an experience that continues to be of concern or to matter to them.

The confusing sensory apprehensions of emerging psychotic symptoms resulted in an unfamiliar and frightening now, with the connection to past and future being blurred for some young people. Amy described how lost she felt, both literally and metaphorically, in the time leading up to her hospitalisation, and this experience was couched within the context of having had an argument with her father and losing her job. This experience of ‘feeling lost’ was one that remained with her throughout her hospitalisation.

_I got on the bus and I had no idea which bus it was so I had no idea where I was going. Then I started texting my cousins and all my friends to see where they were and if they could come and help me. ... I was just lost in town and I saw a million different faces that all looked similar and different. So by the time I got there they’d go away and I thought it was them. And of course I would be getting these messages at the same time and thought they were just around the corner._ (Amy, p. 1)

The confusing sensory experience of seeing and hearing things that were not there occurred in the context of seeking connection with family and friends and the hope that they could help. Alternately, Max’s emerging symptoms of mania were experienced as a return to his former sense of self that had been hidden by depression.

_I couldn’t really describe why at the time I seemed a lot happier about things which was the biological time phase of going from depression into a manic_
Phase. ... And then gee, I seemed a lot more happier in myself, a lot more energetic and everything, and just back to my old self. And I was like, wow, I never thought I would get out of that depression and I did it all by myself and I thought this was awesome!... I had this massive party which I never did before, but it was good. And I did this stand up comedy routine and all this stuff...

(Max, p. 1)

Despite the emerging mania, Max clearly linked his present experience with his past, both pre- and post-depression, and his own sense of agency which projected future potentialities.

Uncertainty, unpredictability and insecurity are temporal features of the young people’s experience of hospitalisation and illness. Psychotic illness significantly challenges the continuity of the young people’s lives as they are thrown into unfamiliar territory and each responded to this uncertainty in different ways. Chloe, who had been transferred to the psychiatric ward after being involved in a car accident, described missing the reality of her life.

> I think I was missing reality. It’s like you get in [to hospital], it’s like you’re in some other world, But you’re not in reality but everyone outside is and you can’t be out there. I believe they should start taking some kids out even if they’re detained because I believe that you need to be able to stay in touch with your life so you can be healthy and get better. (Chloe, p. 3)

Chloe reveals that her experience of illness and hospitalisation was part of but did not dominate her reality which lay beyond the walls of the psychiatric ward.

Remaining connected to this reality was an important part of her being-in-the-world, and indeed, essential to regaining her health. The manner in which she refers to her
life is temporal in nature. It implies a past and projects forward to the not-yet that is beyond the hospitalisation. Chloe did not define what getting better might look like, and at the time of the interviews, which was twelve months after her first discharge from hospital, although she continued to live with symptoms of psychosis, they did not define her sense of self.

The way in which the routine of the psychiatric ward was conceptualised differed significantly between the young people and the nurses. The young people spoke of the routine and the way in which they engaged with activities over time. They described the routine in clock time as a series of nows.

*It was like being locked up in a prison cell. We had dinner at 5, lunch at 12, breakfast at 8 or whenever we got up. Whenever we got up we would pretty much be doing something 9 to 12 and then from 12 to 3 and then from 3 to 6 was our own time. Some days would be different, we would go to the gym. We’d have dinner at 5 and pretty much free time until 9 o’clock and then we’d have to go to bed. It sucked, especially when you’re a smoker and they wouldn’t let you out for a smoke.* (Amy, p. 4)

Amy clearly articulated the routine of the ward, which was coloured by the experience of containment and lack of choice. Joe found the repetitiveness of the routine and the static nature of the space influenced his relationships with others in a negative way.

*It was really repetitive staying in the same place and it’s hard to remember, but it seems like one long, long time, you know. Yeah, like really repetitive stuff, like doing nothing, there’s nothing to do but watch TV and eat food. ... It was really irritating. It was like sending you crazy! It was like, really, you*
know, literally like [laughter] you’re being really paranoid in the place, you know, really sketched out around people, like how paranoid is that! (Joe, p. 2)

Joe’s relationships with others became unpredictable and uncertain leading him to distance himself from both his peers and the staff. Max expressed the uncertainty and insecurity related to his past and future that he experienced once his mania subsided and in the context of the reduced activity of the ward.

I was just bored, nothing to do just lying on my bed wondering, oh crap! I just felt really guilty about the money I owed everybody. I was just like, what am I going to do with my life now? And I just quit Year 12, how am I going to do uni? That was the perception I had at that time. I realised much later that I didn’t need Year 12 to do what I wanted to do. (Max, p. 10)

The unsteadiness and existential anxiety Max experienced in the absence of his previously ceaseless activity spoke to the significance of the future for his sense of self. He demonstrates what Heidegger calls anticipatory resoluteness, a Being-towards his possibilities, a mark of authentic being.

In authentic existence, possibilities as well as its actualities are meaningful. The abstract and idealistic formulations of pure reason ... [are unified] with the immediate and limited world of actual existence. ...This has been phenomenologically interpreted as ‘anticipatory resoluteness’ (Gelven, pp. 167-168)

The fundamental phenomenon of time is the future, the possibility of the not-yet (Heidegger, 1992). Though the not-yet does not exist, it is essential to human existence.
As a human being, I have a future. This means that the future is significant to me. It is because of my possibilities that the future is significant; in fact, ultimately, my ability to have possible ways of Being is what the future means.

(Gelven, 1989, p. 182, original emphasis)

The process of determining the time for discharge was one which caused most of the young people much uncertainty and this often resulted in conflict with staff. The impact of the coercion involved in these young people’s hospitalisation was reflected again as they moved towards discharge. The unpredictability and lack of control that Amy experienced throughout her hospitalisation was reinforced in the decision making process regarding her discharge.

‘Cause my friends had left the day before me and there was nobody there for me anymore, so I pretty much knew I was going home. I don’t know why I stayed there that long. Yeah, and every day they talked about me going home. And they just bullshit to you. ‘If you’re all right in 2 more days you can go.’ Or ‘So you’re going to have to see what the review says in 3 more days.’ Or ‘We now have to wait 3 more days.’ And that went on for 2 ½ weeks. I was really excited to go home every 3 days and then it would be like ‘No, you can’t go.’

(Amy, p. 5)

However, Amy’s temporal understanding about discharge was strongly linked with her relationship with her peers, yet this stood in conflict with the assessment of her mental state that would have been guiding the decision making of the clinical staff. The staff remained focussed on calendar time while Amy was alluding to the loss of key relationships and the impact this would have on her continued presence in the ward.
Other young people managed their relationships with staff in order to actively move toward discharge. Sara consciously used distance and space to affect the staff perception of her mental state and promote discharge. Her understanding that “It’s easy to act normally when you’re not actually in close contact with someone” (Sara, p. 6) speaks to both her motives and her caution in developing a relationship with staff. With discharge as the primary motivator, her relationships with staff remained superficial with little opportunity for therapeutic interactions through active distancing.

When asked what advice she would give other young people who may be hospitalised following first episode psychosis, Amy also advocated for the use of distance and silence as a means of fast tracking discharge.

*Just stay out of their way and get out as fast as you can [laughter]. And try to be as quiet as you can. The more you go on about things, the more they want to keep pressuring you into other things and they just take more time at getting you out.* (Amy, p. 8)

Through the use of active distancing, the young people were attempting to make what was uncertain even to the staff, that is the time of discharge, certain.

Uncertainty also dominated the family members’ experience of the move towards discharge. Julie described her fears for her son’s future as the period of hospitalisation stretched out.

*Initially I didn’t know how long he’d be in [hospital] for. I thought it’d be a day or two. But then they said, ‘Oh look, he might be in for two weeks.’ And that was scary, just thinking he might be in for two weeks. And then it ended up*
being about ten days. That was the first time ... when they said ‘Oh his first episode’ and that’s when it hit me and I said, ‘Well what do you mean, his first episode?’ And that’s when it really hit me, that this is going to be an ongoing thing. And that’s when I, I actually started to cry then, and I was very upset because I remember thinking, just how often is this going to happen? When’s it going to happen and what’s the prognosis for his future? ... I just thought it was the drugs and if he didn’t take them anymore, it’d be okay. But they [staff] said you know it could just come back for no reason. And it has come back for no reason. They said, ‘Let’s just take one day at a time.’ (Julie, p. 3)

The focus on calendar time and the common language implication of the terminology used in first episode psychosis, that there will be a subsequent episode, resulted in the staff missing the temporal complexities of Julie’s distress. Julie was referring to a lifetime that was integrally intermixed with hers as a parent. She commented on the quality of information about psychosis that they were given and the care that was provided to her son, but her ongoing fears for his future were not addressed as she was encouraged to ‘take one day at a time.’ This indeterminacy about the future reflects that of the young people, and results in Julie’s unsteadiness and anxiety about her Being-in-the-world as a parent.

The nurses also spoke of discharge as being a key objective, with the concept of care in the least restrictive environment dominating the decision making. This concept of minimising hospitalisation stems from the early intervention and prevention discourse discussed in Chapter Three in which the aim is to minimise the isolation and trauma of hospitalisation. There is a diametrical tension for nurses between the provision of asylum or refuge, and seeing hospital as primarily a psychologically
unsafe place.

[You] are also making sure that the client gets the best possible treatment so that makes it the best recovery possible, but we also want them out as soon as possible, just as much as they want to get out as soon as possible. It always feels like a big juggling act – you’re always walking a fine line between providing good nursing care and wanting them to get back to their life.

(Nicola, p. 5)

Here Nicola verbalises the struggle between the provision of care which is relational in nature and fundamental in nursing, and the focus on the lowest possible length of stay which is driven by the clock time of medical and economic processes.

Time is a very dominant concept in nursing, indeed in Western health care generally (Jones, 2001). Clock and calendar time guides the shifts nurses work, and the tasks, schedules and procedures that occur within those shifts. It guides the regulation of the nursing profession which occurs annually through the Australian Health Professionals Regulatory Authority. The nature of time that is asserted by the prevailing culture is also associated with power and the potential for dominance (McGrath & Kelly, 1992, cited in Jones, 2001). Those cultures or organisations that consider the influence of time as key to its values tend to dominate those that do not. It has been argued that the dominance of medicine relates to its strong orientation to time, whereas nursing, with its focus on holistic care, does not tend to consider the nature of the influence of time.

In nursing our temporal behaviour is still dominated by the temporal culture of medicine, a culture rooted deeply in clock time, which is both a precondition and a vital tool for medical science. (Jones, 2001, p. 153)
In this study, consideration of clock-time featured strongly in the nurses’ discourse; the time taken to admit the young person, the scheduling of activities to keep the young people busy, the length of time young people may spend in seclusion, and the importance of keeping the admission as short as possible. All of the nurses referred to the policy-driven practices that required them to monitor and document activity in clock time, but only two referred to the temporal nature of the young people’s experience in hospital. The historicity of the young people’s experience relating to their hospitalisation was not addressed and, while the impact of their illness on future potentialities was acknowledged, there was no challenge to this limitation of horizons. Indeed, the nurses contributed to this limitation by not assisting the young people to maintain their connectedness with friends and school. While the nurses problematised this disruption in relationship and saw it as having long lasting effects for the young people affected by psychosis, their concerns about breaching confidentiality and overriding the authority of the parents left them paralysed, thereby missing an opportunity to both address the stigma associated with mental illness in the community and maintain the important peer connection. The nurses’ focus was on the now, on how the young person’s body was responding to pharmacological treatment and the reduction of positive symptoms, while the concerns of the young people and family members related to the past and future.

**Summary**

Heidegger’s notion of temporality is fundamental to the Being of human beings and speaks to the significance of the temporal world. Human experience is not just focussed on the present, but rushes ahead to the future and reaches back to the past. It is the historicity and tradition of the past and the potentialities of the future that influence our preoccupation with the present. Time is not lived fundamentally as
quantifiable, linear time. In this chapter I have explored the complexities of temporal understandings of the time and space of hospitalisation as experienced by young people with first episode psychosis.

The concept of safety or refuge in the space that is the psychiatric ward was viewed by young people and nurses from very different perspectives. The level of coercion involved in the young people’s journey to hospital compounded the fear relating to the frightening and confusing sensory apprehensions they were experiencing, and this was carried through into the space of the psychiatric ward. The young people described feelings of both safety and fear in their experiences on the ward, in relationship with nurses, family members and peers. Some found the relational space between young people and nurses helped to ameliorate the fear associated with being thrown into a foreign environment. Others consciously used distance to try and control the nurses’ ability to accurately perceive their mental state. In this study the nurses focussed primarily on clock time, privileging it above the temporal understandings of the young people. Hence, the young people’s concerns regarding the trauma of the past and the uncertainties of the future were not validated or addressed.

In the final chapter which follows, the thesis as a whole is reviewed and summarised. I will also discuss the boundaries of the study and suggest new opportunities for further research.
Chapter 9: Conclusion

In this final chapter, the thesis as a whole is reviewed and the findings summarised, with implications for those helping young people who have been hospitalised with first episode psychosis and their families. The limitations of the study will be discussed and recommendations for further research in the area of hospitalisation in first episode psychosis and relevant nursing practice. The chapter ends with the claim that the phenomenon of hospitalisation as experienced by young people with first episode psychosis is accessible and these understandings add to nursing knowledge.

In this study I was interested in being hospitalised, not as a simple description of something that happened, but as a description of how the experience continued to be present to the young participants, and how it was witnessed by family members and nurses. I was interested in the young people’s understanding of the experience and the meaning they gave to it within the context of their world. In this study I circled the phenomenon of hospitalisation, exploring it from different textual locations, with the young people’s experience remaining firmly at the centre. While there has been a prodigious amount of research in the area of first episode psychosis and early identification and intervention, the majority of this research has been undertaken within the scientific or empirical discourse. This has resulted in the issue of hospitalisation being discussed in the context of the symptomatology of psychosis and the response to treatment modalities. The nature of hospitalisation itself remained undisclosed.

The phenomenological method of inquiry was chosen as means to explore the phenomenon of hospitalisation, not to identify causal factors or explanations, but to
explore a deeper understanding of hospitalisation and how it is connected to human existence. The study was conducted with the premise that understanding this phenomenon as expressed by young people provides insights essential to nurses who care for them in inpatient settings. It privileged young people as the experts in their lives who demonstrated their capacity to differentiate between their experience of psychosis and their experience of hospitalisation, though each experience is braided with the other.

The work of phenomenologists Martin Heidegger and Kelly Oliver guided the research process and the analysis of the data. While there has been criticism of the use of interpretive phenomenology in nursing research, it became increasingly clear during this study that phenomenology provided a strong platform from which to understand this phenomenon of hospitalisation. It enabled me as the researcher to step aside from the assumptions within the medical model about the experience of first episode psychosis, and it provided space for the Being of the young people and their family members to shine through without being overwhelmed by the illness discourse. Interpretive phenomenology also acknowledges that the existential anxiety related to our thrownness. In this study I have reflected both the similarities and differences of the experience of hospitalisation of the young people, and of the witnessing of this by family members and nurses.

The process of becoming unwell with a psychotic illness and being hospitalised is a complex time within a time. Everyday processes are altered, with thoughts and activity being sped up, slowed down or distorted. Relationships with family and friends are disrupted. The future becomes uncertain and insecure. For many young people who are experiencing psychosis, this is all occurring within a context of
coercion and control, resulting in them being thrown into the space that is the psychiatric ward, a foreign and unfamiliar environment.

The experience of the young people in this environment has a significant impact on their Being-in-the-world. The trauma and fear associated with the challenge to their sensory apprehensions and the subsequent enforced control came with them into the ward and influenced their response within that environment and their relationships with staff. Their understandings of their situation were not acknowledged or validated as the understandings of modern psychiatry were imposed. While it is understood that processing trauma requires more time than a single admission provides, the psychiatric ward has the potential to provide a safe place to have this experience validated and for young people and family members to begin to understand its impact on their sense of self.

For the young people particularly, understandings about their relationship with the world and with others are challenged, not only by the stigma associated with mental illness, but also by the self-stigmatisation that results from socialisation in our community. This was experienced as a major challenge to their sense of self and their own agency, an issue that they struggled with as part of their hospitalisation. The distance this created from family and friends was reinforced by the stigmatising practices within the psychiatric ward of limiting family visits and not providing the support required to maintain contact with friends. The young people’s fears for both the past and the future were a key feature of their experience of hospitalisation, but neither of these was addressed within their hospital stay. The limitation of future possibilities that is part of the psychiatric discourse about the experience of psychosis was acknowledged by the nurses as a concern, but this did not translate into nursing
interventions that would challenge the social issues that lead to poor outcomes. The relationship between young people and nurses is central to engendering hope and broadening future potentialities.

Young people’s experience of hospitalisation was essentially temporal in nature, with past and future concerns influencing their preoccupation with the present. For family members too, the trauma related to the experience of the emerging psychosis and their fears about the indeterminacy of the future preoccupied their present. This contrasted strongly with the focus of the nurses which was firmly on the now, how the young person was responding to pharmacological treatment and the reduction of positive symptoms in order to move as quickly as possible towards discharge. The concept of the space of the psychiatric ward as a place of asylum or refuge was put aside in lieu of a focus on the management of risk. The underlying assumption in early intervention discourses that the psychiatric ward is essentially a psychologically unsafe place results in a tension for nurses between the provision of care that is fundamentally relational and the policy-driven risk management practices that view safety as a one dimensional concept.

Discussion about Oliver’s concept of witnessing in providing a space from which young people and their family members can be heard occurred against the backdrop of Heidegger’s concept of care as solicitude. It was argued that witnessing reflects an ethics of care that is implicit in nursing. In bearing witness to the experience of hospitalisation for these young people, nurses create a space in which the young people’s experience is validated and enables them to connect with their own agency in addressing the trauma of becoming unwell and being hospitalised, and their fears for the future. Only from such a space is it possible for them to bring together the
young people’s apprehensions of their illness and hospitalisation with their own clinical understandings of psychotic illness and treatment. Nursing needs to attend to the tension between its roles in support of psychiatry and the social and ethical directives at the centre of care and witnessing. Heidegger’s notion of care as solicitude and Oliver’s related concept of witnessing provides a way for nursing to move beyond the observational or custodial notion of care.

The young people and family members’ understandings of the experience of hospitalisation raised some challenges to commonly held beliefs in psychiatry with regard to first episode psychosis. The lack of insight is said to be a key feature in the experience of psychosis, and therefore assumptions are made about the capacity of young people to truly understand what it is that they are experiencing. In this study, the young people were able to clearly articulate their experience of becoming unwell with psychosis and differentiate its effects from those of hospitalisation. While the experience of emerging psychosis was one of confusion and fear as sensory apprehensions became uncontrollable, the experience of hospitalisation was temporal in nature, dealing with the trauma of the past and the uncertainty of the future in the context of altered relationships in the present. While the nurses’ focus was on the theoretically derived concept of ‘lack of insight’, understandings of the young people remained unrecognised and continue to be invisible.

**Limitations of the Study**

As with any phenomenological study, this account of the data is one possible way of understanding and interpreting the narratives of the young people’s experience of hospitalisation. “Understanding is the attempt to recapture and reconstruct the inner creative process, to grasp another’s thoughts” (Parker, 2011, p.82).
In recognising my prior understandings of this issue before commencing the study, I have in some way acknowledged the historicity and tradition of my past that had the potential to influence this research. However, while I have tried to remain conscious of aspects of my past and experience at each stage of the research, it is not possible to extricate them from the research process completely.

This study relied on interpretation of texts that were the narratives of the young people, family members and nurses. Understanding these texts as a whole requires consideration of the individual parts, just as understanding the individual parts requires a sense of the whole (Packer, 2011). A circular relationship exists between the text and its context, history and tradition. Heidegger (1962) suggested that a circular relationship exists between understanding and interpretation. Understanding is the unspoken comprehension of a situation, and interpretation is the communication of that understanding. In verbalising what is implicit, inconsistencies in what is understood and what is not overt become evident. This, I believe, has led to new understandings.

In this study, participants were required to have experienced hospitalisation following the diagnosis of psychosis, were stabilised and living in the community, and that they spoke English. Consistent with the methodology, the young participants were not representative of all young people who have been hospitalised with first episode psychosis in terms of age, gender and socioeconomic status. These participants met the criteria for inclusion and, they were invited to join the study from a relatively small pool by a third party. While there were equal numbers of males and females in the group of young people, this cannot be said of the family members, all of whom were female. The recruitment of family members was
dependent in the first instance on the willingness of the young people to invite them, and then on the willingness of the family members to be involved. For a number of reasons some young people chose not to invite their family members to be involved in the study, and some parents also chose not to be involved in the study for reasons that were not disclosed to me.

In this study, the diagnosis of psychosis was not the major focus, so there was no control regarding more specific diagnostic categories. Some of the young people had been diagnosed with bipolar disorder or schizophrenia subsequent to their hospitalisation. Some had received a number of diagnoses during the acute and recovery period. Self identification as a person who had experienced hospitalisation after the first experience of psychosis was accepted as adequate criterion. The focus in this study was the experience of hospitalisation rather than the diagnosis.

This study was conducted in a small mental health service for young people in Australia. This limits the study in so far as it occurred in a specific organisation and in a particular culture. However, the findings are arguably transferable to others. In order to maintain confidentiality, it was necessary to remove any identifying information. I believe I have done so in a way that has not detracted from or changed the accuracy of the data. In addition, as psychosis is a low prevalence illness and the chosen philosophical basis for the study was interpretive phenomenology, the participant numbers were characteristically small. While the findings cannot be generalised to all young people who are hospitalised with first episode psychosis, they do provide an understanding of ways in which nurses can witness and respond to these experiences in a supportive way.
Suggestions for Future Research

This study explored the experience of hospitalisation for young people with first episode psychosis. It was a step towards deepening the understanding of what it is to be hospitalised as a young person with mental illness. As demonstrated in Chapters 1 and 3, there is a significant gap in the research regarding the subjective experience of hospitalisation, particularly one that privileges the voices of young people.

This study reveals a number of areas for further research. There is a need for research regarding the ways in which nurses bear witness to the experience of young person and family members in both inpatient and community mental health settings. Exploring the use of witnessing with therapeutic intent in nursing would build on previous sociological and feminist research. Further research would explicate the use of witnessing as a way to help young people explore and understand the traumatic experience of becoming unwell with a psychotic illness.

In this research, the experience of stigma and self-stigmatisation was a significant aspect of the young people’s experience of hospitalisation. It resulted in isolation and separation from family and friends and this was augmented and sustained by ward practices. Further research is required regarding practices that help to maintain social relationships even in the acute setting, thereby promoting positive outcomes.

Concluding Comments

This thesis has explored the phenomenon of hospitalisation as experienced by young people with first episode psychosis. It was predicated on the belief that it would be beneficial to nursing practice to understand the nature of this phenomenon as described by young people and witnessed by family members and nurses. Through understanding and interpretation, I have circled the phenomenon to expose the
temporal and relational elements of the experience that has the potential to inform nursing practice. In the circling of this phenomenon, the complexities of the experience are evident. As Max expressed this in the title of this thesis, “If life were a line, mine would be a circle.” While further phenomenological research is required to build on these findings, the challenge now is to translate this knowledge into an ethics of mental health nursing practice and policy development that is more sensitive to the needs of young people and their families.
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Appendix 1: Ethics Approvals

8th March 2006

Ms M. McPevy

Re: Understanding the experience of Hospitalisation of Young People with first episode
Psychosis. REC1777/12/06

Thank you for your letter dated 16th February 2006 in which you responded to matters raised by the
Research Ethics Committee at its December 2005 meeting. All matters have been
addressed with the exception of Point 8 regarding the Consent Form. For legal reasons, the Consent
Form should either be complete on the one page, or include clauses and the signature section on the
second page. The study may proceed once you have forwarded the revised Consent Form.

1. remind you approval is given subject to:
   • immediate notification of any serious or unexpected adverse events to subjects;
   • immediate notification of any unforeseen events that might affect continued ethical acceptability of
     the project;
   • submission of any proposed changes to the original protocol. Changes must be approved by the
     Committee before they are implemented;
   • immediate advice, giving reasons, if the protocol is discontinued before its completion;
   • submission of an annual report on the progress of the study, and a final report when it is
     complete. Please note it is your responsibility to provide these reports – without reminder from the
     Ethics Committee.

Approval is given for three years only, and if the study is more prolonged than this, a new
renewal will be required. Please note the approval number above indicates the month and year
in which approval expires and it should be used in any future communication.

If University of Adelaide personnel are involved in this project, an chief investigator must
submit a Human Research Approval notification form (available at:
http://www.adelaide.edu.au/research/ethics/human/guidelines/) within 14 days of receiving this
ethical clearance to ensure compliance with University requirements and appropriate
notification.

Yours sincerely

Chair

RESEARCH ETHICS COMMITTEE
Dear Ms McEvoy

Project 3448  Understanding the experience of hospitalisation for young people with first episode psychosis

At its meeting on 15 May 2006 the Social and Behavioural Research Ethics Committee considered the application you submitted in respect of the above project.

I am pleased to inform you that the proposed project has been approved, for the period of time requested, on the basis of the information contained in the application and its attachments. However, please attend to the following before beginning data collection:

(i) Provide a copy of the amended Letter of Introduction. Reference is made to it being attached to the application but it wasn’t.

(ii) Reconsider response to item D4 as it mentions. There doesn’t appear to be any mention of it elsewhere. If the response to L4 is correct, amend supporting documentation where necessary.

(iii) Delete reference to participation affecting progress on course of study from the Consent Form for participants over 18 years.

(iv) Delete reference to participation affecting treatment or service from the Consent Form for nursing staff.

(v) Ensure that contact details of counselling services are provided to all participants.

In accordance with the undertaking you provided in the application, please inform the Social and Behavioural Research Ethics Committee, giving reasons, if the research project is discontinued before the expected date of completion and report anything which might warrant review of ethical approval of the protocol. Such matters include:
- serious or unexpected adverse effects on participants;
- proposed changes in the protocol; and
- unforeseen events that might affect continued ethical acceptability of the project.
May I draw to your attention that, in order to comply with monitoring requirements of the National Statement on Ethical Conduct in Research Involving Humans an annual progress and/or final report must be submitted. A copy of the report pro forma is available from the SBREC website http://www.flinders.edu.au/research/Office/ethics/socialbehavioural.html.

Yours sincerely,

[Signature]

Sandy Huxtable
Secretary
Social and Behavioural Research Ethics Committee

cc: Dr Trudy Rudge, Nursing & Midwifery
Ms Pat Barkway, Nursing & Midwifery

NB: If you are a scholarship holder and you receive funding for your research through the National Health & Medical Research Council please forward a copy of this letter to the Head, Higher Degree Administration and Scholarships Office, for forwarding to the NHMRC.
13 May 2008

Professor Trudy Rudge
Faculty of Nursing and Midwifery
Mallett Street Campus – M02
The University of Sydney

Dear Professor Rudge

Title: Understanding the experience of Hospitalisation of Young People with first episode Psychosis (Ref. No. 10967)

PhD Student: Ms Monica McEvoy

Your application was reviewed by the Executive Committee of the Human Research Ethics Committee (HREC), and in doing so has ratified your study to include the PhD student – Ms Monica McEvoy.

The Executive Committee acknowledges your right to proceed under the authority of the Research Ethics Committee.

Please note, this ratification has been given only in respect of the ethical content of the study.

Any modifications to the study must be approved by the Health Service Research Ethics Committee before submission to the University of Sydney Human Research Ethics Committee.

Yours sincerely

Gail Briddy
Senior Ethics Officer
Ethics Administration

cc Ms Monica McEvoy,
THE EXPERIENCE OF HOSPITALISATION FOR YOUNG PEOPLE WITH FIRST EPISODE PSYCHOSIS

Information Sheet for Potential Research Participants (under 18 years)

NAME OF RESEARCHER: Monica McEvoy

I am conducting research as part of my studies at The University of Sydney. The research is inquiring into what hospitalisation is like for young people experiencing first episode psychosis. During this research I will be talking with young people who have had this experience, a member of their family or significant other, and nurses who have had the experience of caring for young people with first episode psychosis in inpatient settings. Knowing more about this experience from a variety of perspectives will assist health professionals in the future to understand and plan care for young people with this first episode psychosis.

If you agree to be involved in the study you will be asked to participate in an interview with myself about what the experience of hospitalisation was like for you when you were first diagnosed with psychosis. The interview will be done in an informal way at a time arranged as suitable for us both, and in an agreed place. The interview will be audio taped to ensure that I record your information accurately. The interview will be transcribed and you will be provided with an opportunity to change or add further information as required. A second interview may be required to clarify specific aspects of the information.
I will ask you to nominate a family member or significant other who spent time with you during the hospitalisation who is willing to be interviewed about their experience as witness to your hospitalisation.

If you agree to participate in the study, you have the right to several things:

1. You can choose not to answer a particular question or terminate the interview at any time. You can request to turn off the tape recorder at any time. You have the right to withdraw from the study at any time. If you feel upset you can stop the interview. We will not go on unless you want to and if you feel you would like to talk to someone about how you are feeling, I will have a list of names and numbers of people you can contact.

2. The information collected will be used only for my research. You will not be identified in my report and all individual identifying information will remain confidential. You will be asked to choose a false name as a code. All research information will be kept in a secure place accessible only to me. Myself and a typist whom I may employ to assist in the transcription will only listen to the tapes.

3. You have a right to a copy of our interview, either as a tape or as a written transcript, if you wish. When the study is written up, a copy will be retained at the The University of Sydney library.

Any questions regarding the research can be directed to me, Monica McEvoy, telephone number: 0418 891 564.

If there are questions I have not been able to answer to your satisfaction, or if you have a complaint to make as a participant, please write to the Ethics Administration, University of Sydney, or the Research Ethics Committee, [Name] Health Service who will investigate your complaint and inform you of the results of their investigation. The Committees can be contacted at the following addresses and telephone numbers:

Senior Ethics Officer
Ethics Administration
University of Sydney
NSW 2006
Ph: 02 9351 4811

The Secretary
Research Ethics Committee
Research Institute
[Hospital name]
CONSENT FORM FOR PARTICIPATION IN RESEARCH
(by interview)

I …………………………………………………………………………………………………………………………………………………

being under the age of 18 years hereby consent to participate as requested in the interview process for the research project on the experience of hospitalisation for young people with first episode psychosis.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to my information and participation being recorded on tape
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
   • I may not directly benefit from taking part in this research.
   • I am free to withdraw from the project at any time and am free to decline to answer particular questions.
   • While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
   • There is no payment for my involvement in the study.
   • I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

6. I have had the opportunity to discuss taking part in this research with a family member or friend.

7. I require the consent of my parent/guardian to be involved in the study.
Participant's signature……………………………………Date…………………………

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name……………………………………………………………………

Researcher's signature……………………………………Date…………………………

I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

Participant's signature……………………………………Date…………………………

I, the participant whose signature appears below, have read the researcher’s report and agree to the publication of my information as reported.

Participant's signature……………………………………Date…………………………
THE EXPERIENCE OF HOSPITALISATION FOR YOUNG PEOPLE WITH FIRST EPISODE PSYCHOSIS

Information Sheet for Potential Research Participants (over 18 years)

NAME OF RESEARCHER: Monica McEvoy

I am conducting research as part of my studies at the University of Sydney. The research is inquiring into what hospitalisation is like for young people experiencing first episode psychosis. During this research I will be talking with young people who have had this experience, a member of their family or significant other, and nurses who have had the experience of caring for young people with first episode psychosis in inpatient settings. Knowing more about this experience from a variety of perspectives will assist health professionals in the future to understand and plan care for young people with this first episode psychosis.

If you agree to be involved in the study you will be asked to participate in an interview with myself about what the experience of hospitalisation was like for you when you were first diagnosed with psychosis. The interview will be done in an informal way at a time arranged as suitable for us both, and in an agreed place. The interview will be audio taped to ensure that I record your information accurately. The interview will be transcribed and you will be provided with an opportunity to change or add further information as required. A second interview may be required to clarify specific aspects of the information or if you become tired or upset and wish to continue the interview at another time.

I will ask you to nominate a family member or significant other who spent time with you during the hospitalisation who is willing to be interviewed about their experience as witness to your hospitalisation.

If you agree to participate in the study, you have the right to several things:
4. You can choose not to answer a particular question or terminate the interview at any time. You can request to turn off the tape recorder at any time. You have the right to withdraw from the study at any time. If you feel upset you can stop the interview. We will not go on unless you want to and if you feel you would like to talk to someone about how you are feeling, I will have a list of names and numbers of people you can contact.

5. The information collected will be used only for my research. You will not be identified in my report and all individual identifying information will remain confidential. You will be asked to choose a false name as a code. All research information will be kept in a secure place accessible only to me. Myself and a typist whom I may employ to assist in the transcription will only listen to the tapes.

6. You have a right to a copy of our interview, either as a tape or as a written transcript, if you wish. When the study is written up, a copy will be retained at the University of Sydney library.

Any questions regarding the research can be directed to me, Monica McEvoy, telephone number: 0418 891 564.

If there are questions I have not been able to answer to your satisfaction, or if you have a complaint to make as a participant, please write to the Ethics Administration, University of Sydney, or the Research Ethics Committee, [Name] Health Service who will investigate your complaint and inform you of the results of their investigation. The Committees can be contacted at the following addresses and telephone numbers:

Senior Ethics Officer
Ethics Administration
University of Sydney
NSW 2006
Ph: 02 9351 4811

The Secretary
Research Ethics Committee
Research Institute
[Hospital name]
CONSENT FORM FOR PARTICIPATION IN RESEARCH
(by interview)

I ……………………………………………………………………………………………………………………………………………
being over the age of 18 years hereby consent to participate as requested in the interview process for the research project on the experience of hospitalisation for young people with first episode psychosis.

4. I have read the information provided.

5. Details of procedures and any risks have been explained to my satisfaction.

6. I agree to my information and participation being recorded on tape

4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.

5. I understand that:
   • I may not directly benefit from taking part in this research.
   • I am free to withdraw from the project at any time and am free to decline to answer particular questions.
   • While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
   • Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
   • There is no payment for my involvement in the study.
   • I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

6. I have had the opportunity to discuss taking part in this research with a family member or friend.
Participant's signature…………………………………Date…………………………

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name……………………………………………………………………

Researcher's signature…………………………………..Date…………………………

7. I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

Participant's signature…………………………………Date…………………………

8. I, the participant whose signature appears below, have read the researcher’s report and agree to the publication of my information as reported.

Participant's signature……………………………………Date…………………………
Appendix 2: Information and consent forms

Nurses

The University of Sydney

ABN 15 211 513 464

Trudy Rudge
Professor of Nursing

Room 4.01
Faculty of Nursing and Midwifery M02
University of Sydney NSW 2006
AUSTRALIA
Telephone: +61 2 9351 0700
Facsimile: +61 2 9351 0605
Email: t.rudge@usyd.edu.au
Web: www.usyd.edu.au

THE EXPERIENCE OF HOSPITALISATION FOR YOUNG PEOPLE WITH FIRST EPISODE PSYCHOSIS

Information Sheet for Potential Research Participants by Interview
(Nursing Staff)

NAME OF RESEARCHER: Monica McEvoy

I am conducting research as part of my studies at the University of Sydney. The research is inquiring in to what hospitalisation is like for young people experiencing first episode psychosis. During this research I will be talking with young people who have had this experience, their family members, and nurses who have had the experience of caring for young people with first episode psychosis in inpatient settings. Knowing more about this experience from a variety of perspectives will assist health professionals in the future to understand and plan care for young people with this first episode psychosis.

If you agree to be involved in the study you will be asked to participate in an in depth interview of approximately one hour duration about your experience of providing nursing care to young people with first episode psychosis. The interview will take place at a time and place that is suitable to us both. The interview will be audio taped to ensure that I record your information accurately. The interview will be transcribed and you will be provided with an opportunity to change or add further information as required. A second interview may be required to clarify specific aspects of the information.

If you agree to participate in the study, you have the right to several things:

1. You can choose not to answer a particular question or terminate the interview at any time. You can request to turn off the tape recorder at any time. You have the right to withdraw from the study at any time.
2. The information collected will be used only for my research. You will not be identified in my report and all individual identifying information will remain
confidential. You will be asked to choose a false name as a code. All research information will be kept in a secure place accessible only to me. Myself and a typist whom I may employ to assist in the transcription will only listen to the tapes.

3. You have a right to a copy of our interview, either as a tape or as a written transcript, if you wish. When the study is written up, a copy will be retained at the University of Sydney library.

Any questions regarding the research can be directed to Researcher, Monica McEvoy, telephone number: 0418 891 564.

If there are questions I have not been able to answer to your satisfaction, or if you have a complaint to make as a participant, please write to the Ethics Administration, University of Sydney, or the Research Ethics Committee, [Name] Health Service, who will investigate your complaint and inform you of the results of their investigation. The Committee can be contacted at the following address and telephone number:

Senior Ethics Officer
Ethics Administration
University of Sydney
NSW 2006
Ph: 02 9351 4811

The Secretary
Research Ethics Committee
Research Institute
[Hospital name]
CONSENT FORM FOR PARTICIPATION IN RESEARCH
(by interview)

I …………………………………………………………………………………………………………………(Nursing Staff Member)

being over the age of 18 years hereby consent to participate as requested in the interview process for the research project on the experience of hospitalisation for young people with first episode psychosis.

7. I have read the information provided.

8. Details of procedures and any risks have been explained to my satisfaction.

9. I agree to my information and participation being recorded on tape

4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.

5. I understand that:
   • I may not directly benefit from taking part in this research.
   • I am free to withdraw from the project at any time and am free to decline to answer particular questions.
   • While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
   • There is no payment for my involvement in the study.
   • I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

6. I have had the opportunity to discuss taking part in this research with a family member or friend.
Participant's signature……………………………………Date…………………………

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name……………………………………………………………

Researcher's signature………………………………………………Date………………

7. I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

8. 
Participant's signature……………………………………Date…………………………

9. I, the participant whose signature appears below, have read the researcher's report and agree to the publication of my information as reported.

10. 
Participant's signature……………………………………Date…………………………
The University of Sydney

Appendix 2: Information and consent forms

Families

THE EXPERIENCE OF HOSPITALISATION FOR YOUNG PEOPLE WITH FIRST EPISODE PSYCHOSIS

Information Sheet for Potential Research Participants (Family Members) under 18 years

NAME OF RESEARCHER: Monica McEvoy

I am conducting research as part of my studies at The University of Sydney. The research is inquiring into what hospitalisation is like for young people experiencing first episode psychosis. During this research I will be talking with young people who have had this experience, a member of their family or significant other, and nurses who have had the experience of caring for young people with first episode psychosis in inpatient settings. Knowing more about this experience from a variety of perspectives will assist health professionals in the future to understand and plan care for young people with this first episode psychosis.

If you agree to be involved in the study you will be asked to participate in an interview with myself about the experience of witnessing the hospitalisation of your family member or friend who has experienced first episode psychosis. The interview will be done in an informal way at a time arranged as suitable for us both, and in an agreed place. The interview will be audio taped to ensure that I record their information accurately. The interview will be transcribed and you will be provided with an opportunity to change or add further information as required. A second interview may be required to clarify specific aspects of the information.

If you agree to participate in the study, you have the right to several things:

1. You can choose not to answer a particular question or terminate the interview at any time. You can request to turn off the tape recorder at any time. You have the right to withdraw from the study at any time. If you feel upset you can stop the interview. We will not go on unless you want to and if
you feel you would like to talk to someone about how you are feeling, I will have a list of names and numbers of people you can contact.

2. The information collected will be used only for my research. You will not be identified in my report and all individual identifying information will remain confidential. You will be asked to choose a false name as a code. All research information will be kept in a secure place accessible only to me. Myself and a typist whom I may employ to assist in the transcription will only listen to the tapes.

3. You have a right to a copy of our interview, either as a tape or as a written transcript, if you wish. When the study is written up, a copy will be retained at the University of Sydney library.

Any questions regarding the research can be directed to me, Monica McEvoy, telephone number: 0418 891 564.

If there are questions I have not been able to answer to your satisfaction, or if you have a complaint to make as a participant, please write to the Ethics Administration, University of Sydney, or the Research Ethics Committee, [Name] Health Service, who will investigate your complaint and inform you of the results of their investigation. The Committees can be contacted at the following addresses and telephone numbers:

Senior Ethics Officer
Ethics Administration
University of Sydney
NSW 2006
Ph: 02 9351 4811

The Secretary
Research Ethics Committee
Research Institute
[Hospital name]
CONSENT FORM FOR PARTICIPATION IN RESEARCH
(by interview)

I …...........................................................................................................................(Family Member/Friend)

being under the age of 18 years hereby assent to participate as requested in the interview process for the research project on the experience of hospitalisation for young people with first episode psychosis.

10. I have read the information provided.

11. Details of procedures and any risks have been explained to my satisfaction.

12. I agree to my information and participation being recorded on tape.

4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.

5. I understand that:
   • I may not directly benefit from taking part in this research.
   • I am free to withdraw from the project at any time and am free to decline to answer particular questions.
   • While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
   • Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
   • There is no payment for my involvement in the study.
   • I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

6. I have had the opportunity to discuss taking part in this research with a family member or friend.
7. I require the consent of my parent/guardian to be involved in this study.

Participant's signature……………………………………Date……………………

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name……………………………………………………………………

Researcher's signature…………………………………………………………Date……………………

7. I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

8.

Participant's signature……………………………………Date……………………

9. I, the participant whose signature appears below, have read the researcher’s report and agree to the publication of my information as reported.

10.

Participant's signature……………………………………Date……………………
## Appendix 3: List of Counselling and Support Services for Each Young Person Participating

<table>
<thead>
<tr>
<th>List of Counselling Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>All details deleted to maintain confidentiality.</td>
</tr>
<tr>
<td>Child &amp; Adolescent Mental Health Services</td>
</tr>
</tbody>
</table>

| Adult Mental Health Services |

| [Name]Youth Health Services |

| Other Health Services |

| Support Groups |
Appendix 3: Counselling & support services

Appendix 4: Mind Map