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A phenomenological examination of the meaning of resilience as described by people who experience schizophrenia

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A phenomenological examination of the meaning of resilience as described by people who experience schizophrenia

By

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ABSTRACT

The aim of this study was to understand the meaning of resilience as described by people who experience schizophrenia. Building resilience is now a component of the professional standards for mental health nurses within Australia and of the mental health care delivered by health services. Very little is known about resilience in the context of schizophrenia and this thesis does not examine how to build resilience, it lays a foundation upon which to construct. Establishing the meaning of resilience for those who experience schizophrenia is an important first step in building understanding for both professionals and health services.

Fourteen people who live with schizophrenia engaged in semi-structured interviews and described the meaning of resilience for them. NVivo 9™ data analysis software was used to capture the interview transcripts and to manage the process of interpreting text using van Kaam's Psychophenomenological Method (Eppard & Anderson 1998). Analysis of participant data revealed that the meaning of resilience as described by people who experience schizophrenia is embedded within the struggle of striving to overcome the challenges brought by schizophrenia.

Within the struggle, resilience means adopting an attitude of *striving* to overcome the severe adversity caused by the experience of schizophrenia. The process of striving enables the person to learn about themselves, the effect of the schizophrenia illness on them, and how to manage it in the context of the life they want to live. Striving to overcome schizophrenia involves struggle, including repeated backwards steps and during this, the person seeks out and uses supportive people and resources. This also comes with challenges and resilience emerges from the process of competently overcoming these challenges, in the quest for improvement. The person then seeks out

new challenges and experiences and grows life in ways unrelated to just living to manage the illness.

An implication of the findings for mental health professionals is that struggling, taking risks and exercising responsibility, even if it leads to a setback, are all important components of the meaning of resilience for people who experience mental illness.

DECLARATION OF ORIGINALITY

The research and discussion submitted in this thesis is my own work. It contains no material that has been submitted to any other tertiary institution for any other award. Due acknowledgment has been made for any material prepared by other people or institutions and a complete list of these references is presented within this thesis. Any contribution made to the research by colleagues with whom I have worked at the University of Wollongong or elsewhere during my candidature is fully acknowledged.

I agree that this thesis be accessible for the purpose of study and research in accordance with the normal conditions established by the Executive Director, Library Services or nominee, for the care, loan and reproduction of theses.

Signed by Susan Ann Liersch: _____   _____
On:__12___/__5__/_2013____

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I would like to sincerely thank my supervisors, Professor Lorna Moxham, Associate Professor Peter Caputi and Associate Professor Janette Curtis. Your patience, support and guidance through what has been at times, a very difficult journey, are very much appreciated.

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PUBLICATIONS AND PRESENTATIONS EMANATING FROM THIS RESEARCH

Manuscripts published

Liersch, S, Moxham, L, Caputi, P & Curtis, J 2012, 'Schizophrenia and resilience: what does it mean?' *Australian Nursing Journal,* vol. 20, no. 2, p. 41.

Liersch, S, Curtis, J & Caputi, P 2011, 'People with schizophrenia can become resilient while recovering', *Journal of Human Development, Disability and Social Change,* vol. 19, no. 1, pp. 85-94.

Liersch, S, Curtis, J & Caputi, P 2008, 'Do the concept of resilience and the experience of schizophrenia go together?' *International Journal of Mental Health Nursing,* vol. 17, s. 1, p. 18.

Conference presentations

Liersch, S 2011, 'People with schizophrenia can become resilient while recovering', paper presented at the *International Conference, Resilience: new intervention perspectives on rehabilitation,* 27th-28th April, Montreal, Canada.

Liersch, S 2010, 'Is resilience an appropriate concept to attach to schizophrenia?' paper presented at the *Coping, resilience and hope building, Asia Pacific Regional Conference,* 9th-11th July, Brisbane, Australia.

Liersch, S 2008, 'Do the concepts of resilience and schizophrenia go together?' paper presented at the *34th Annual Australian College of Mental Health Nurses International Conference,* 6th-10th October, Melbourne, Australia.

Liersch, S 2007, 'Resilience and life-time risk in schizophrenia', paper presented at the *13th Annual Hunter Mental Health Conference: resilience, key to thrive,* 18th May, Newcastle, Australia.

DEFINITION OF KEY TERMS

ACRONYM	TERM	DEFINITION
ABS	Australian Bureau of Statistics	Australia's national statistical agency.
APA	American Psychiatric Association	Society representing psychiatric physicians within the United States of America. Responsible for the creation of diagnostic classification criteria (DSM).
ASRB	Australian Schizophrenia Research Bank	An organisation that seeks volunteer enrolment from people with schizophrenia to participate in research related to schizophrenia.
Consumer	Consumer of mental health services	People who use mental health services.
DSM	Diagnostic and Statistical Manual	The Diagnostic and Statistical Manual is a classification system for mental disorders which was created by the American Psychiatric Association. The DSM-IV-TR is the version currently in use within Australia and the DSM-V is scheduled for release in May 2013.
GSAHS	Greater Southern Area Health Service	Health service supporting research, now known as the Illawarra Local Health District.
ICD	International Classification of Diseases	The International Classification of Diseases is the standard diagnostic tool for epidemiology, health management and clinical purposes which was created by the World Health Organisation. The ICD-10 AM is the version currently in use within Australia.

ACRONYM	TERM	DEFINITION
HREC	Human Research Ethics Committee	Institutional committee that reviews the ethics of research proposals.
MHA	Mental health assessment	An interview between a mental health professional and a person experiencing a mental health problem for the purpose of screening the person's state of mental health using a reliable and valid process.
NSW	New South Wales	The state of Australia in which the research was conducted.
NVivo 9^{TM}	NVivo	Qualitative data management software distributed by QSR International.
PPM	Psychophenomenological Method	A phenomenological method of data interpretation created by van Kaam.
SRR	Schizophrenia Research Register	See Australian Schizophrenia Research Bank.
UOW	University of Wollongong	Institution supporting this research.

CHAPTER ONE

RESEARCH OVERVIEW

This thesis reports on an examination of the *meaning* of resilience as described by people who experience a mental illness known as schizophrenia. It explores the lived experience and privileges the voices of the people who manage on a daily basis with schizophrenia. It is their story, it is their journey. It is documented in the form of a PhD thesis.

The motivation for this study arose in 2004 from my own experiences as a newly graduated nurse working within a mental health acute care setting. I was struck when hearing people being given a diagnosis of schizophrenia. I witnessed a solemnity to the occasion, framed by the quiet, almost grave presence of the professionals which created the impression that there was some terrible unspoken message. The experience created a heavy, deadened feeling in my body. Many times, I walked out of an interview room with a newly diagnosed person and felt impelled to lift them in some way, to grab what seemed like a sense of shock for the person and to turn it into some hope for the future. My own world-view insisted to me that nothing is all bad and that there is something good to be grasped from the situation and with which to move forward, in every situation, no matter how dire it may feel. Despite this, I had no professional language to use to convey this and I did not possess any knowledge of what a positive future could be for a person on a journey with schizophrenia. This left me in a state of despair not only for the person who had been diagnosed, but also for my future as a mental health nurse. I knew I could not sustain a career that included professional despair and lack of hope. I needed to be part of, or even initiate a different, more positive experience. I

went in search of positive information about schizophrenia out of determination to improve the situation.

I embarked upon a literature search for positive information about schizophrenia which was a precursor to the decision to conduct the research work of this thesis. A comprehensive search of health, medical and behavioural science databases was undertaken and the results clearly revealed a lack of inquiry into positive aspects of schizophrenia, however I judged this to be a lack of documented inquiry, rather than a lack of positive aspects to schizophrenia. Within the search results, were three articles describing studies which examined the experience of schizophrenia from the perspectives of people diagnosed with it (Andresen, Oades & Caputi 2003; Geanellos 2005; Tooth et al. 2003). The word *resilience* was used within these articles and my understanding of resilience at that time was that it meant a good outcome. *Resilience* therefore had an impact upon me as something worth investigating for its potential to deliver positive knowledge on the experience of schizophrenia and thus became the stimulus for the work of this thesis.

The next step was to carry out a literature search on the relationship between schizophrenia and resilience, an inquiry which resulted in the following interpretations;

1)   *Resilience* as a field of inquiry actually emerged through the surprising findings of research into the outcomes of children raised by a parent diagnosed with schizophrenia (Bleuler 1978; Garmezy 1971; Rutter et al. 1976). Findings revealed that the majority emerged relatively unscathed from their deprived circumstances to lead successful adult lives (Garmezy 1971). The study of resilience therefore became the study of successful outcomes despite severe

adversity and moved to the field of child development (Garmezy & Devine 1984; Garmezy & Rutter 1983; Rutter et al. 1976; Werner 1989). These inquiries did not investigate resilience in the context of people diagnosed with schizophrenia and resilience inquiry largely moved away from schizophrenia at this point.

2)   One view of the development of schizophrenia is that it is linked to a state of being vulnerable (Das et al. 2001; Falkai & Moller 2012; Gispen-de Wied & Jansen 2002) and vulnerability is hypothesised as being at the opposite end of a continuum with resilience (Garmezy 1993), leading to the suggestion that people who develop schizophrenia are demonstrating vulnerability rather than resilience (Masten & Obradovic 2006).

3)   No explanation was found for why resilience might be a component of recovery from schizophrenia although it is regarded to be a vital element in successful recovery (Andresen, Oades & Caputi 2011).

Building the resilience of people who live with mental illness was called for in Australian national as well as state and territory mental health planning (Australian Health Ministers 2003; Commonwealth of Australia 2009; Council of Australian Governments 2006) and was also a component of the professional standards for mental health nurses within Australia (Australian College of Mental Health Nurses 2010) and yet there was no identifiable evidence to inform this, therefore, there was a significant gap in the research and in the literature. Therefore, to be able to make 'resilience building' part of my clinical practice as a mental health nurse, contributing to addressing the gap was highly desirable. I wanted to be part of the solution, not perpetuate what I

saw as a problem and decided to begin at the beginning and to find out first hand, from people who experience schizophrenia, what resilience means for them.

Research purpose and aims

The purpose of this research is to contribute knowledge to an identified gap in the literature.

The aim of this research was to identify the meaning of resilience as described by people who experience schizophrenia.

Research question

The question that guided this study was:

> *What is the meaning of resilience as described by people who experience schizophrenia?*

Rationale and significance of the study

Building resilience for people who experience mental illness is a component of planning for mental health service delivery and also of professional standards for mental health nurses within Australia. To 'build' resilience, one must understand what it means, however, as previously stated, very little is known about resilience within the context of mental illness in general or schizophrenia in particular.   Therefore, it is anticipated that the findings of this study will contribute to this gap in knowledge and as such this thesis presents findings for *the meaning of resilience as described by people who experience schizophrenia*.

The thesis does not examine how to build resilience, it lays a foundation upon which to construct. It deliberately examines meaning.

Organisation of the thesis

The thesis is presented in six chapters. This chapter has provided a brief introduction, background and significance of the study as well as outlines the manner in which the thesis has been structured.

Chapter one provides an overview of the research which included the motivation for the study, the purpose and aim and the research question.

Chapter two presents a background to the study which due to its length, has been divided into three sections. Section one explores and discusses the mental illness known as schizophrenia and the way in which schizophrenia is understood within the practice of mental health professionals. Section two presents the phenomenon of resilience as discussed within literature and section three discusses what is known of the relationship between schizophrenia and resilience.

Chapter three describes the qualitative phenomenological research design which was chosen to interpret an answer to the research question and provides a detailed explanation of the way in which this was achieved. It includes a comprehensive description of the research design, the participants, and method of data collection as well as ethical considerations. It also includes a detailed description of the approach used to draw conclusions which drew upon van Kaam's method of phenomenological analysis.

In chapter four, the main findings of the research are explained. Detail is provided regarding the meaning of resilience for people who experience schizophrenia along with a number of elements that nest within supportive or challenging areas.

Chapter five discusses and interprets the findings and explains them while comparing them with the knowledge presented in the background chapters and also with other relevant national and international literature. Within the discussion, participant voices have been used to explain the key findings.

Chapter six summarises the purpose and aims of the research and offers some considerations for mental health professionals to utilise within their mental health practice and also some considerations for mental health service delivery. Limitations of the study are also discussed and recommendations for further studies are made.

For ease of reading, many of the tables and figures have been repeated within the work, rather than being added as appendices.

A word on nomenclature

This study was based on the belief that research involving vulnerable populations should be with them and not about, on or for them. As such, the consumer position of 'nothing about me without me' (Nelson et al. 1998) has been at the forefront of thinking within the conduct of this thesis. Accordingly, I have used participant voices in the form of direct quotes to reduce the distance between the meaning provided by participants, my interpretation of that within the research methodology and the findings that are discussed within this thesis. Crossley and Crossley (2001, p. 1478) define 'voice' as 'the articulation of one's experiences and views regarding a specific topic'. Furthermore, the position taken is that the researcher is not the official gatekeeper on what is real and what is not and the meaning provided by participants was honoured as being the truth of their experience.

Also importantly, although change is slowly occurring, professional voices have long held the authority position within the field of mental health (Crossley & Crossley 2001) and bringing through the voice of people who have experience of mental illness is important for removing professional inhibition of consumer discourse (Crossley & Crossley 2001, p. 1487).

I have also occasionally used my own voice and spoken in the first person within this thesis to clearly indicate when referring to my own experiences within the research process. Whilst researchers strive through their choice of methodology to bracket themselves out of the research process I do not wholly subscribe to that position and feel that it is impossible to separate the two. The world is not made up of separate objects but instead is an intimate connection of vibrations of energy and relationships (Greene 2003). Therefore, I have declared my involvement by writing in the first person.

I have also deliberately chosen to write the word schizophrenia with a small s. As this thesis demonstrates schizophrenia is only a part of a person, not the whole of the person. By giving the word schizophrenia a small s there is less emphasis on the illness and greater focus on the person.

CHAPTER TWO

Section one: Schizophrenia

Introduction

A comprehensive review of the literature was undertaken to understand resilience and the role it is thought to play in schizophrenia. Whilst there was abundant literature discussing resilience within other life contexts, no literature could be identified to shed light on the meaning of resilience for people who experience schizophrenia.   This demonstrated a significant gap in the literature and indicated that knowledge could be contributed through inquiry. Thus the aim of this research was to identify the meaning of resilience as described by people who experience schizophrenia.

The chapter has been organised to discuss the concepts of mental health and mental illness and specifically schizophrenia as a mental illness, and further, to explore the diagnosis and treatment for this particular illness. An analysis of published evidence related to resilience is also presented. The chapter concludes with a discussion of resilience in the context of a person living with schizophrenia.

Mental health and mental illness

Within psychiatry and psychology literature, mental health and mental illness are offered as distinctly different concepts, despite the fact that they are frequently used as de facto descriptors for each other (Keyes 2005). Mental health and mental illness are not two ends of the same continuum, but rather, are considered to be two distinct trajectories (Keyes 2005; Manderscheid et al. 2010; Westerhof & Keyes 2010; World Health Organisation 2004). A state of *mental health* has been defined by the World Health Organisation (2004, p. XVIII) as:

A state of wellbeing in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to his or her community.

The key components of the WHO definition, as viewed by Westerhof and Keyes (2009) are *emotional well-being, psychological well-being* and *social well-being.* A state of *emotional well-being* is a subjectively described feeling of happiness and satisfaction with life. *Psychological well-being*, as defined by Ryff and Keyes (1995) has six elements; self-acceptance, purpose in life, autonomy, positive relations with others, environmental mastery and personal growth. *Social well-being* as defined by Westerhoff and Keyes (2010) has five dimensions that when met indicate that an individual is functioning optimally in society (Westerhof & Keyes 2010). They are social coherence, social acceptance, social actualisation, social contribution and social integration. In comparison, determining a widely accepted definition for mental illness is difficult.

Mental illness

Current definitions of mental illness lack precise boundaries with regard to what clearly is or what is not a mental illness (Stein et al. 2010). This is demonstrated by differences in definitions related to mental illness in each Australian state and territory Mental Health Act (Moxham, Robson & Pegg 2012). The definition of mental illness, within a medical context is a pattern of symptoms that manifest in an individual's moods, thoughts or cognitions and which are recognised behaviourally or psychologically (American Psychiatric Association 2012; Stein et al. 2010). The symptoms cause significant distress and disability or impairment in an important area of functioning for the individual (Stein et al. 2010). A mental illness is considered to have an underlying psychobiological or neurological dysfunction and is not an expected response to

common stressors or losses (Stein et al. 2010). Schizophrenia is considered a mental illness.

Mental illness is not the absence of mental health, any more than mental health is the absence of mental illness (World Health Organisation 2004). In a research project to diagnose and measure mental health, Keyes (2005) studied 3,032 adults in the United States of America (USA), in a post-stratified cohort which was representative of the adult proportions of the USA population for age, gender, education, marital status, race and residence. Keyes (2005) defined a state of mental health as above average functioning in the dimensions of emotional well-being, psychological well-being and social well-being. Furthermore, three levels of mental health were defined; *languishing*, *moderate* and *flourishing*. *Languishing* is considered to be below average functioning in the dimensions of mental health (emotional well-being, psychological well-being and social well-being), *moderate* mental health is considered as above-average functioning within those same dimensions, and *flourishing* individuals are said to exhibit high levels of functioning. Two scales of subjective well-being and eleven scales of positive functioning were used to diagnose and measure these three levels of mental health (Keyes 2005).

Keyes and Haidt (2002) identified that not only do people with a mental illness experience moderate levels of mental health but that individuals without a mental illness experience languishing mental health. That is, mentally ill individuals can exhibit above average levels of mental health and mentally healthy individuals can exhibit symptoms of mental illness. Therefore, despite assumptions that a state of mental health assumes no mental illness, mental health and mental illness are considered to be

two continua, not a single continuum (Manderscheid et al. 2010; Westerhof & Keyes 2010).

A state of mental health is not the natural outcome of treatment to remove symptoms of mental illness (Manderscheid et al. 2010). Treatment aimed at lessening the behavioural or psychological symptoms of mental illness does not provide the person with a sense of self-acceptance, autonomy or purpose in life necessary to meet the definition of mental health (Keyes 2005; Manderscheid et al. 2010; Westerhof & Keyes 2010). Manderscheid et al (2010) propose that while mental health and mental illness are distinctly different, there are connections between mental illness and mental health. Programs using models concordant with principles of person centredness (Barker 2001), a strengths-based focus (McCormack 2007; Peterson & Seligman 2004; Rapp & Goscha 2006; Shanley & Jubb-Shanley 2007) or the recovery movement (Buchanan-Barker & Barker 2006; Repper 2000; Shepherd, Boardman & Slade 2008) can create a bridge between illness and health because their methods address the correlates of mental health and not just the symptoms of mental illness (Manderscheid et al. 2010). Responding resiliently to challenges is also considered an element of mental health (Friedli 2009; Keyes 2005; Keyes 2009; Westerhof & Keyes 2010). Being resilient is thought of as possessing the ability to cope with adversity and to grow and flourish as a result (Friedli 2009; Keyes 2005; U.S. Department of Health & Human Services 1999). Flourishing and growth are also elements of mental health.

Mental health and mental illness are distinct experiences. Mental health is a subjective state of wellbeing characterised by feelings of happiness derived through living a life that is autonomous and satisfying and includes personal growth. Mental illness is a pattern of distressing symptoms affecting mood, thought and behaviour which interfere

with daily functioning (Stein et al. 2010). People who live with mental illness can experience above average levels of mental health and those members of society who may be perceived as mentally healthy individuals can exhibit symptoms of mental illness (Westerhof & Keyes 2010). Therefore, while an individual is living with symptoms of mental illness, they are also able to live an autonomous life that is satisfying and includes personal growth. Resilience is an element of the ability to cope with and grow past the adversity of mental illness.

The World Health Organisation recognises that the interventions required to assist people to move from mental illness to mental health are lacking within the majority of current treatment systems (Friedli 2009). Researching resilience, as this study does, within the context of mental illness is important for understanding what resilience means with regard to mental health for a vulnerable and disempowered population. Such an understanding can then form the basis upon which interventions can be built.

Schizophrenia

Schizophrenia as a mental illness

Schizophrenia is a mental illness (Mura 2012; Tandon, Nasrallah & Keshavan 2011). The origin of the word schizophrenia is Greek; skhizein means to split and phrën means mind. The name is thus representative of characteristic schisms between thought, emotion and behaviour (Gattaz, Abrahao & Foccacia 2002). These schisms are viewed as the central signs of schizophrenia and are regarded to be undesirable and unwanted disturbances which are historically equated with 'madness' (Gattaz, Abrahao & Foccacia 2002; Porter 1987; Whitaker 2002). As a result of a systematic synthesis of a century of research findings on schizophrenia, Tandon, Keshavan and Nasrallah (2008a) created a list of 'clinical facts' for schizophrenia. These 'facts' are presented in Table 1.

Table 1: Clinical facts of schizophrenia

CLINICAL FACTS OF SCHIZOPHRENIA
o The nosological boundaries between schizophrenia and other mental illnesses are indistinct.
o There is significant heterogeneity in neurobiology, clinical manifestations, course, and treatment response across people.
o Schizophrenia is characterised by a mixture of positive, negative, disorganised, cognitive, psychomotor and mood symptoms.
o The severity of different symptom clusters varies across people and through the course of the illness.
o The onset of psychotic symptoms is usually during adolescence or early adulthood and the age of onset is earlier in males.
o A generalised but highly variable cognitive impairment is present prior to the onset of psychosis and persists during the course of the illness.
o There may be specific impairment in a range of cognitive functions (such as memory, psychomotor speed, attention and social cognition).
o Schizophrenia is frequently a chronic and relapsing disorder with generally incomplete remissions.

(adapted from Tandon, Keshavan & Nasrallah 2008)

However, Chadwick (2009), an author who self-identifies as having experienced schizophrenia, offers the following perspective*;*

> *Schizophrenia is associated with the workings of the creative process, with language, high sensitivity, imaginativeness, enhanced spiritual sensitivity and empathy and these cannot be eliminated without doing serious and irreversible damage to our species.*
>
> (Chadwick 2009, p. x)

Researchers Spaniol, Gagne and Koehler (1997) agree and further state;

> *Who knows what works of literature, music or art, what achievements or what acts of courage and compassion are waiting to be released in every individual who has schizophrenia.*
>
> (Spaniol, Gague & Koehler 1997, p. 5)

The type of 'facts' presented in Table 1 are consistent with viewing schizophrenia as a mental illness, however the quotes of Chadwick and Spaniol, Gagne and Koehler also shown above suggest that the seeds for mental health, may also be present, such as through expression of creativity.

Contributions to the cause of schizophrenia

The cause of schizophrenia is currently unknown. There are purported to be many contributing factors; but despite this, it is largely considered to be genetically based because it aggregates in families (Maier et al. 2002; van Os & Kapur 2009).

Tandon, Keshavan and Nasrallah's (2008) summary of the aggregated findings of published genetic research for schizophrenia identified high heritability, with genetic factors believed to contribute about 80 per cent of the liability for the illness, however, no particular gene has been identified as necessary or sufficient to cause the illness. Many susceptible genes may however contribute to the liability for the illness (Tandon, Keshavan & Nasrallah 2008).

There is around a 10 per cent risk for developing schizophrenia which is associated with having a parent with schizophrenia and a 50 per cent risk if both parents have schizophrenia (Lichtenstein et al. 2009). Therefore, the strongest predictor of developing schizophrenia is an affected first degree relative (Maier et al. 2002; van Os & Kapur 2009). Having a parent with schizophrenia increases the likelihood of developing schizophrenia but is not considered sufficient alone to cause it (Maier et al. 2002). Gottesman (1991) aggregated the findings of many studies examining the genetic risks for developing schizophrenia, shown in Figure 1 (Gottesman 1991) which

despite the publication age are still relevant and being cited today (Gottesman & Hanson 2005; Kapur 2011; Mura 2012).
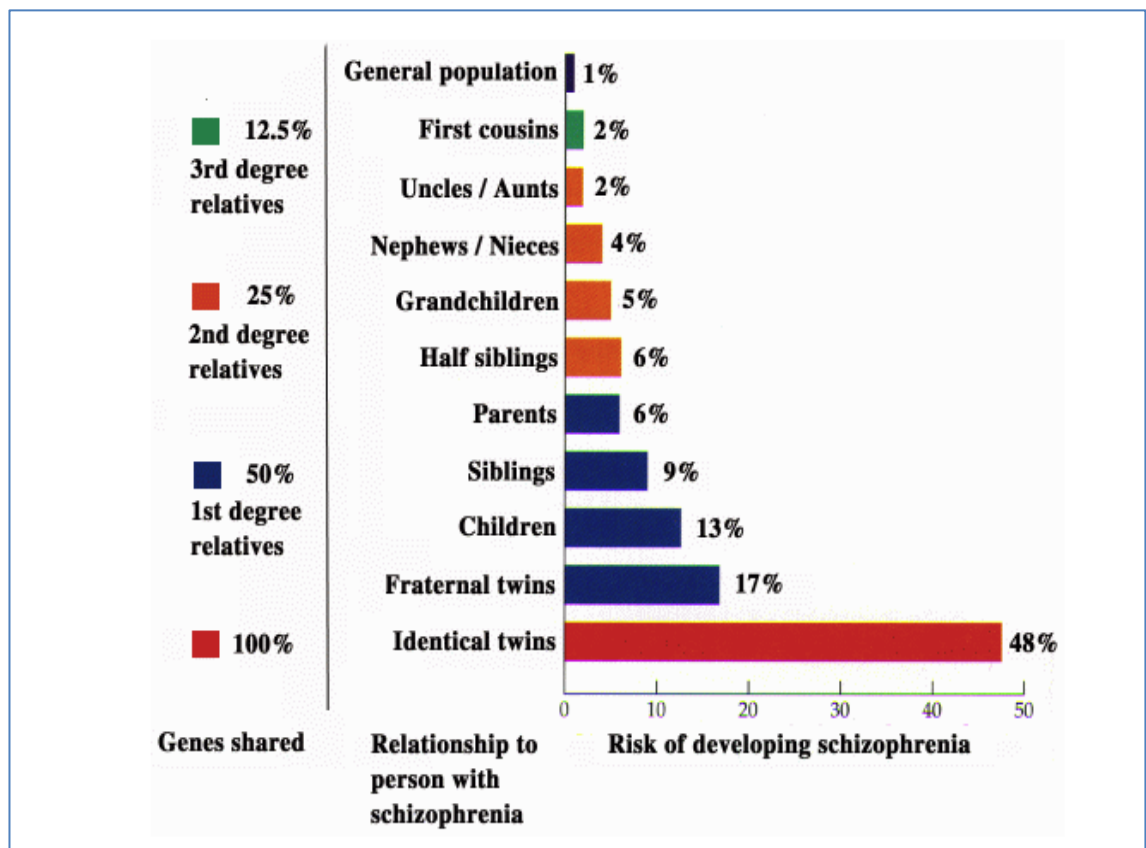
Figure 1: Genetic risks for schizophrenia

Analysis of kinship, adoption and foster-child studies to investigate the heritability of schizophrenia (Farber 1981) supported the genetic hypothesis and also raised questions regarding the potent influence of environmental factors on the onset and content of schizophrenia. Since then, there has been a growing body of research on the influence of environmental factors.

Genetic vulnerability to schizophrenia provides an individual with a threshold ability to cope with stressful events and encountering stress in excess of this tolerance leads to decompensation of mental state to the point where clinically diagnosable symptoms emerge (Tienari et al. 2002). Twins reared-apart studies, where one child was fostered

or adopted away and one child was reared by the biological mother with schizophrenia have found the environment to be a significant predictor in whether a schizophrenic break occurred (Farber 1981; Tienari et al. 2002). A 'schizophrenic break' is the first psychotic episode, and even though it occurs before diagnosis, it is rarely the first emergence of symptoms (Tienari et al. 2002). Many environmental and social factors, for example including, cannabis misuse, perinatal complications and social stress (Keshavan et al. 2008a), have been identified and are thought to incrementally increase the risk for the development of schizophrenia however none have been found sufficient to cause schizophrenia (Tandon, Keshavan & Nasrallah 2008).

As mentioned above, much research has been undertaken to explore the interplay of genetic and environmental factors in the cause of schizophrenia (Caspi et al. 2005; Cougnard et al. 2007; Hänninen et al. 2008; Krabbendam & van Os 2005; Nicodemus et al. 2007; Sei et al. 2007; Szabolcs 2009; Wen-Cheng 2008; Zammit et al. 2007). Within such research is the notion of epigenesis. Epigenesis relates to reciprocal escalation between genetic and environmental factors (Tienari et al. 2002) and is based on the heightening effect of inborn vulnerability and environmental stressors on each other. The environment has an affect on gene expression, rather than on the genes themselves (Rutter 2006a). Within the environment, people's reactions to each other and within the broader social environment are considered to be pivotal to the effect (Rutter 2006a).

A nationwide Finnish study compared 164 adopted-away biological children of parents with schizophrenia with 197 adopted-away biological children of parents without schizophrenia (Tienari et al. 2000). Findings indicated that individuals who were considered to be at genetic risk for the illness, due to having a parent diagnosed with schizophrenia, showed the greatest vulnerability to environmental adversity. Adverse

factors characteristic of the rearing environment which are thought to increase the likelihood of developing the illness when coupled with an inherited risk for developing schizophrenia were; 1) having an intensive or explosive atmosphere in the home, 2) not being acknowledged by parents, 3) having parents in conflict with one another, 4) family insecurity, such as financial, 5) having a narrow range of emotional expression within the family, 6) being dissatisfied with the family, 7) experiencing poor family boundaries, 8) individual enmeshment of problems, and 9) generational enmeshment of problems, for example, trauma from experiences of war (Tienari et al. 2000).

Risk and protective factors

Having one environmental risk factor represents no increase in risk, two factors represents a four-fold increase in risk and four factors are associated with a ten-fold increased risk over normal for development of schizophrenia when coupled with genetic risk (Hafner 2002). Knowledge of risk factors is important for structuring preventative interventions when an increased level of risk is able to be identified, for example, through one or both biological parents having a schizophrenia diagnosis (Ehrenreich & Siren 2002; Jones 2002). Protective factors, such as those which prevent brain disturbance during important perinatal and adolescent developmental periods (Ehrenreich & Siren 2002) and those which improve family relationships (Hafner 2002; Klingberg 2002), have been shown to moderate risk for the onset of schizophrenia and also to support a positive outcome (Rutter 2006b).

'Protection' can occur on biological, psychological, sociological and spiritual levels. Changes to brain tissue related to schizophrenia have been shown in imaging studies to commence in childhood (Keshavan et al. 2008b; Schroder, Bottmer & Pantel 2002) and identification of neuro-protective factors is important for mitigating risk (Ehrenreich &

Siren 2002). Physical exercise and psychotherapy have been shown to reduce the vulnerability of brain tissue and are therefore regarded to be neuro-protective (Ehrenreich & Siren 2002; Lieberman 2007). In particular, exercise at the aerobic level of activity has been shown to increase the volume of the hippocampal area of the brain which is associated with improvements in short term memory (Wobrock, Hasan & Falkai 2012). Psychotherapy aims to improve personal and social functioning in areas such as problem solving through the use of cognitive activities (Spaulding & Nolting 2006). The 'self-perpetuating cascade of abnormal development' (Jones 2002, p. 153) is also a cycle that needs to be broken. An example of this is poor attachment as a result of impaired parenting, which has a cascading effect developmentally (Jones 2002).

To date, research has shown that having a genetic risk for schizophrenia is not sufficient to cause the illness and that other factors are strongly associated, including vulnerability to stress and developmental and social difficulties.

The epidemiology of schizophrenia

One person in every 1,000 will be diagnosed with schizophrenia (Kapur 2011; Mura 2012). A systematic review analysing data from 55 studies across 33 countries revealed that between 1965 and 2001, the incidence of schizophrenia was 15.2 people per 100,000 people per year (McGrath et al. 2004). Variations in incidence revealed higher risk related to urbanicity, migration and male gender (McGrath et al. 2004). The peak period for onset of schizophrenia has been identified as being between 15 and 30 years of age (Howard et al. 2000) with the average age of onset for males being 20 years and for females 24 years (Hor & Taylor 2010; Palmer, Pankratz & Bostwick 2005; Saha, Chant & McGrath 2007). It is thought that equal numbers of males and females develop schizophrenia (Saha et al. 2005; Versola-Russo 2006) however a systematic

review of epidemiological studies identified a 1:4 incidence ratio with males having the higher incidence (McGrath 2006).

Psychiatric illnesses, including the diagnosis of schizophrenia, have not been validated as disease entities (Charney et al. 2002; Hyman 2010; Reed 2010; Tandon, Nasrallah & Keshavan 2011). There are no scientific truths for the relationships among psychiatric disorders or among the symptoms within disorders (Hyman 2010). Diagnosis for various mental illnesses do not identify a homogenous population and therefore people with many different presentations may be captured within one diagnostic group (Taylor et al. 2010a). Subsequently, there is ongoing difficulty prescribing a single universal definition for schizophrenia (Castle & Morgan 2008; Mueser & Jeste 2008) and the diagnostic schedules used to determine schizophrenia are somewhat subjective. However with consistent review processes in place, diagnostic schedules are considered to be becoming increasingly more reliable (Charney et al. 2002; Hyman 2010; Reed 2010; Stein et al. 2010). Epidemiologists assert that there is a failure to consistently use diagnostic interview schedules, instead using 'best guess' (Castle & Morgan 2008, p. 14) and therefore the reliability of data collected may be questioned.

'Secondary schizophrenia', refers to a group of other conditions that present with symptoms similar to that found in schizophrenia, such as drug induced psychosis, neurological conditions, genetic disorders and delirium but which are not schizophrenia (Balan 2011; Hambidge 2005; Mitchell 2011; Sachdev & Keshavan 2010). Without consistent assessment for these conditions as a routine part of the diagnostic process, which is a huge challenge given the subjective nature of a mental health assessment, Hyde and Lewis (2003) estimate that between 5 per cent and 8 per cent of people are diagnosed incorrectly. Screening protocols should rule these conditions out of the

diagnostic process, however, compliance with screening protocols, even when they are in place, is also an issue that has been raised by epidemiologists (Castle & Morgan 2008; Hambidge 2005; McGrath et al. 2005; Mitchell 2011; Mura 2012).

Despite these methodological problems, international epidemiological findings for schizophrenia suggest consistency in illness patterns (Castle & Morgan 2008; Tandon, Keshavan & Nasrallah 2008). A meta-analysis of 188 studies across 46 countries yielded prevalence estimates ranging from 1.3 people per 1,000 to 8.2 people per 1,000 with a median point prevalence of 4.6 per 1,000 people (Saha et al. 2005). Across the world, pockets of low and high prevalence were identified by Saha et al (2005), for example, lower prevalence in developing countries, whereas the World Health Organisation cites prevalence to be similar across the world (Access Economics 2002). Tandon, Keshavan and Nasrallah (2008) found that pockets of low and high prevalence are related to the level of development and the socio-economic classes within countries. Furthermore, those migrating from developing countries have been found to be at higher risk for developing schizophrenia than those from developed countries (Castle & Morgan 2008). Despite the identification of pockets of high and low prevalence across the world, this pattern is not reflected in the overall prevalence data provided by the World Health Organisation. The particular method chosen to estimate prevalence may be one reason for this (Saha et al. 2005).

Schizophrenia is among the 20 leading causes of disability in the world (World Health Organisation 2008b) and although figures on cost are very difficult to determine it is regarded to be one of the most burdensome and costly illnesses (Rössler et al. 2005). The 'burden' as a measure relates to not only what is judged to have been lost, but also what would be gained if the illness were eradicated (Wolff 2007).

The burden of disease related to schizophrenia is broad and costs are difficult to estimate due to methodological problems associated with health economics (McCrone 2007). Burdens though are also inclusive of opportunities lost to individuals who experience the illness, such as poor educational attainment, school difficulties, employment problems (Knapp & Razzouk 2009), lost income, stigma, financial impacts associated with living with a disability (medication and treatment expenses) and higher rates of self-harm and suicide (Access Economics 2002; Ayuso-Mateos 2000; Begg et al. 2007; Knapp & Razzouk 2009). A person with schizophrenia also imposes (albeit unwillingly) costs to family members and carers (McCrone 2007; Rössler et al. 2005). Governments and other organisations who provide services for people who live with schizophrenia also incur costs (Access Economics 2002; Begg et al. 2007; Carr et al. 2004; Knapp, Mangalore & Simon 2004; McCrone 2007). Wolff (2007, p. 67) finds that 'the cost of mental illness is a product of the social norms embedded in the socialisation of the illness and the science underpinning the estimate'. Therefore, costs are a reflection of the degree of departure from 'normalcy' and the rationale for the measurement is to estimate the size of the return journey to 'normal'. Within this calculation, Wolff (2007, p. 67) has identified a 'bevy of assumptions' with regard to prevalence, mortality, morbidity, treatment rates, unemployment and the economic value of an individual with a diagnosis of schizophrenia.

In addition very few evaluations for the indirect costs of schizophrenia have been conducted (Knapp, Mangalore & Simon 2004; McCrone 2007). Many costs are 'hidden', such as unpaid care, lost opportunities and time spent in contact with services (McCrone 2007). Knapp and Razzouk (2009) identified that many of the studies underpinning published economic evaluations of schizophrenia were underpowered in terms of sample size and also not representative of the most expensive and difficult to

treat samples. Therefore, the actual financial burden associated with schizophrenia is enormously difficult to calculate.

The most recent data, which broadly relates to mental illness, rather than schizophrenia in specific, suggests that within Australia, costs associated with mental illness are $20 billion annually, including lost productivity and labour force participation.   The disability associated with mental illness is the leading cause of the loss of healthy years of life (Australian Bureau of Statistics 2009). Fitzgerald et al (2007) conducted a three year study of the direct health care costs in Australia which was part of a larger study also replicated in the United States of America and the United Kingdom.   In Australia, 347 people granted access to their medical and hospitalisation records which allowed calculation of costs associated with both inpatient and outpatient care and medications for the three year period studied. As a result, the average annual societal cost was calculated to be $29,510 per person. Inpatient hospital care was the most expensive portion at 37 per cent of total cost and the indirect costs accounted for 49 per cent, with other costs making up 100 per cent. Knapp, Mangalore and Simon (2004) estimated that inpatient costs accounted for between 28 and 94 per cent of direct health care costs. Whilst within their study, average costs were provided, Fitzgerald et al (2007) also identified that overall results were skewed with 39 per cent of people consuming 80 per cent of resources. This is possibly related to the level of severity of illness, the high costs of inpatient care for the most acutely ill and the highly individual nature of the schizophrenia experience.

 However, the dollar cost is not the most serious burden associated with schizophrenia. As early as in 1911 Eugen Bleuler, who was a pioneering psychiatrist in the field of schizophrenia treatment and research, believed that suicide was the most serious burden

of schizophrenia (Bleuler 1978) and this view has not changed in recent years (Carlborg et al. 2010; Hor & Taylor 2010). Schizophrenia continues to have an unacceptably high suicide rate of four to five per cent of people compared to that of the general population figure of 14.5 per 100,000 people (Carlborg et al. 2010; Saha, Chant & McGrath 2007).

A world-wide meta-analysis of 632 articles studying lifetime suicide prevalence estimates that 4.9 per cent of people diagnosed with schizophrenia will commit suicide, with the majority doing so near illness onset (Palmer, Pankratz & Bostwick 2005). In Australia, estimates are that 40 per cent of people with schizophrenia will make at least one suicide attempt and 10 per cent of those will complete suicide. The highest risk period is identified as within the first two years of experiencing symptoms (Australian Bureau of Statistics 2011; Roy & Pompili 2009), within the first year after diagnosis, during an inpatient admission (Carlborg et al. 2010) or after discharge from care (Access Economics 2002; Australian Bureau of Statistics 2011; Lee & Lin 2009).

A more recent systematic review of 51 studies regarding rates and risk factors for suicide by people with schizophrenia identified a five per cent lifetime risk and also grouped risk factors by type and strength of association with suicide (Hor & Taylor 2010). Factors with a strong association included being young and male with a high level of education (Hor & Taylor 2010). Important predictors are having made previous suicide attempts, the presence of depression or having active hallucinations and delusions (Carlborg et al. 2010; Hor & Taylor 2010). External factors, not specifically related to schizophrenia suggest that the most high risk proximal factor is an acute social crisis coupled with an impulsive or aggressive personality (Carlborg et al. 2010).

The suicide rate for people with schizophrenia is believed to be linked with a pervasive hopeless and pessimistic view of the illness and the belief that having schizophrenia is a lifetime sentence (Pompili et al. 2009). One study found an association with the age and gender of the treating psychiatrist (Lee & Lin 2009). Portraying a hopeful and more optimistic view of schizophrenia as well as discussing a positive pathway at the time of diagnosis is important for engaging the person effectively with treatment and decreasing the number of suicides linked to hopelessness (Hor & Taylor 2010).

The symptoms of schizophrenia

Bleuler's early view of schizophrenia as 'a group of diseases' defined by a number of basic but quite diverse symptoms that are present in everyone diagnosed with it continues to be supported (Tandon & Maj 2008; Tandon, Nasrallah & Keshavan 2009). However, individual diseases within this constellation have yet to be delineated (Tandon, Nasrallah & Keshavan 2009).

Symptoms are said to be diverse because they include individualised distortions of thinking, distortions of perception, cognitive impairments, motor abnormalities, changes to motivation, difficulties in communication and restricted expression of emotions (American Psychiatric Association 2000; Tandon, Nasrallah & Keshavan 2009). Not all people experience all symptoms, nor all of the time. Different symptoms can be experienced across different episodes for the same person and acuity of symptoms will also differ across episodes for the same person and across people, which once again demonstrates the complexities and challenges of accurate diagnosis (Davidson & McGlashan 1997; Tandon, Nasrallah & Keshavan 2009). Symptoms have been divided into symptom dimensions of *positive, negative, cognitive, disorganisation, mood and motor* by Tandon, Nasrallah and Keshavan (2009) and examples are shown in Table 2.

Table 2: Symptom dimensions and symptoms of schizophrenia

DIMENSION	SYMPTOM	EXPERIENCE
Positive symptoms Distortions to reality that influence functioning and mark the formal onset of schizophrenia	Delusions Hallucinations	Holding false, fixed beliefs; delusions of being persecuted are most frequent. Delusional content is influenced by the person's life and socio-cultural context. False perceptions in any of the five senses; sight, hearing, taste, touch, smell. Auditory hallucinations of hearing voices conversing among themselves or commenting on the person are the most common. The tone is most often threatening or accusatory.
Negative symptoms Blunting or loss of a range of emotions and the ability to express those emotions	Loss of motivation Poverty of speech Inability to experience pleasure Lack of initiative Lack of interest Reduced social drive	These can be primary symptoms; related to the schizophrenia illness itself, or secondary symptoms; caused by neuroleptic medications, environmental deprivation or depression.
Cognitive impairments	Episodic memory Processing speed Verbal fluency Attention Working memory	Cognitive impairments are believed to be present prior to the formal appearance of schizophrenia.
Disorganisation Fragmentation of normal thought processes Disorganised behaviour	Circumstantiality Tangentiality Incoherence Word Salad Incongruous affect Inappropriate attire	Loss of normal, logical sentence structure, with frequent changes in the direction of conversation in which the train of thought is lost. Internally felt mood and expression of that mood don't match. Clothing is out of context with the circumstance.
Mood symptoms	Increased emotional arousal and reactivity Depression	An excitable mood co-existing with the presence of positive symptoms. Significant depressive symptoms are commonly experienced with negative symptoms at some point in the illness and are believed to be worsened by the use of neuroleptic medications or illicit drugs.
Motor symptoms	Positive symptoms Negative symptoms	Excessive or purposeless physical activity - unusual postures, strange mannerisms, excessive repetition or lack of variation in movement. Slowing of physical activity - catatonic states, states of stupor.

(Tandon, Nasrallah & Keshavan 2009)

The experience of the symptoms of schizophrenia has been described in the following poem written by Sandy Jeffs, a consumer consultant, author and poet who identifies as a person who lives with schizophrenia;

BRUTAL MADNESS

Brutal Madness, come no more to my home.
Do not cast your shadow over my door,
Lest you steal me away
Taking me into your arms
To transport me to your far-off prison.

I do not like your morbid abode.
I do not like your turgid space.
I do not want to be with your friends
Who intimidate my reason with lies.

Your brutality to my repose and dignity
Empties my soul of its calm,
And leaves me abandoned in a madhouse
Where Sister Sorrow weaves a tapestry
Of woe and suffering that knows no boundary.

I am no more of this cosmos,
I am no more of this life
When you, Brutal Madness,
Divine to plunder all my senses' defences.

(Jeffs 2000, p. 12)

Many of the clinical observations contained in Table 2 can be seen within Jeff's descriptions of her experiences, for example, the line 'who intimidate my reason with lies' and the positive symptoms of delusions and hallucinations; the line 'empties my soul of its calm' and the increased emotional arousal resulting from mood changes, and finally, the line 'where sister sorrow weaves a tapestry' and the negative symptoms of depression and loss of a range of emotions.

Diagnosing schizophrenia

Making a diagnosis of a psychiatric disorder entails making relative judgement of the experience of another person and how that compares with the normative values of the sociocultural setting of the diagnostic act.

(Robertson & Walter 2007, p. 797)

Schizophrenia is currently diagnosed under two separate classification systems; one created by the World Health Organisation, named the International Classification of Diseases (ICD) (World Health Organisation 1993) and the other developed by the American Psychiatric Association (APA), named the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association 2000). Both classification systems are constantly reviewed and updated. The APA is shortly to release the fifth version of the DSM and the WHO will release the ICD version 11 (Reed 2010; Stein et al. 2010), however as this research relates to the experiences of people who have been already been diagnosed with schizophrenia under current and even previous diagnostic versions, the future of classification systems is not discussed.

The structured classification of symptoms, as represented in the above, is considered necessary for creating a common understanding of diseases and disorders that can be shared not only within communities, cities and countries but also globally (World Health Organisation 2008a). Classification is also considered useful for identifying

illnesses, providing education, designing and delivering treatment and for research and epidemiological purposes (Australian Government 2012; Reed 2010). The WHO's ICD diagnostic classification system is the global standard for health reporting and clinical applications (Reed 2010; World Health Organisation 1993). Despite this, the psychiatric professions in many countries use the American Psychiatric Association's DSM (Ebert 2008; Reed 2010; Stein et al. 2010). The reasons behind professional's choices of diagnostic tool are many and varied and are beyond the scope of this discussion, however, it is important to note that psychiatric classification for an individual has significant implications that reach well beyond the boundaries of a single diagnostic act.

In the absence of pathophysiological certainty, psychiatric diagnoses are socially constructed (Robertson & Walter 2007; Wolff 2007; Young 2009). Therefore the diagnostic classification of psychiatric illness has inherent problems such as being based on values rather than facts (Robertson & Walter 2007; Stein et al. 2010). An example provided by Robertson and Walter (2007) is the diagnosis of acute delirium, which is a physical illness confirmable through tests using validated measures. In comparison, schizophrenia is diagnosed by considering patterns of behaviour (observed or not) that deviate from socially constructed norms. These structured classification criteria, which are essentially statements set against socially constructed norms are problematically regarded to be reliable (Garb 2005; Reed 2010; Robertson & Walter 2007; Stein et al. 2010).

The 'truth' of the diagnostic term 'schizophrenia' is that it is an accepted set of beliefs which are value-laden (Kapur 2011) and which are judged against a backdrop of

normative socio-cultural perspectives (Robertson & Walter 2007) and that propel a person into a mentally sick role accompanied by stigma (Robertson & Walter 2007).

In the absence of definitive scientific evidence, the diagnosis of schizophrenia is made through a series of interviews by a person qualified and empowered to make psychiatric diagnoses, such as a psychiatrist. During the interview process, an extensive set of questions are asked, known as a mental health assessment (MHA). Questions include understanding the person's thinking, perceptions and mood (American Psychiatric Association 2000). In addition, observations are made about the person's appearance, behaviour and speech and judgements are made about the individual's degree of awareness of their illness (known as insight) and the quality of the decisions they are likely to make as a result of their level of insight (APA 2000). The findings of the assessment, which are derived from the observations and interpretations of the practitioner or clinician and the dialogue provided by the person being interviewed together with collateral information from family members and friends when available, are matched with diagnostic criteria for schizophrenia from the chosen diagnostic tool.

Table 3 outlines the criteria for schizophrenia according to the current version of the DSM, the DSM-IV-TR, and Table 4 outlines the diagnostic criteria of the ICD-10 and discussion on these tables then follows.

Table 3: DSM-IV-TR diagnostic criteria for schizophrenia

	DSM-IV-TR DIAGNOSTIC CRITERIA FOR SCHIZOPHRENIA
A	**Characteristic symptoms:** Two or more of the following, each present for a significant portion of time during a one-month period: ■ delusions ■ hallucinations ■ disorganised speech (for example frequent derailment or incoherence) ■ grossly disorganised or catatonic behaviour ■ negative symptoms (for example affective flattening, alogia, or avolition).
B	**Social/occupational dysfunction:** Since the onset of the disturbance, one or more major areas of functioning, such as work, interpersonal relations, or self-care, are markedly below the level previously achieved.
C	**Duration:** Continuous signs of the disturbance persist for at least six months. This six-month period must include at least one month of symptoms (or less if successfully treated) that meet Criterion A.
D	**Exclusion** of schizoaffective disorder and mood disorder with psychotic features.
E	**Substance/general medical condition exclusion:** the disturbance is not due to the direct physiological effects of a substance (for example, a drug of abuse, or a medication) or a general medical condition.
F	**Relationship to a pervasive developmental disorder:** If there is a history of autistic disorder or another pervasive development disorder, the diagnosis of schizophrenia is made only if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated).

(American Psychiatric Association 2000)

Table 4: ICD-10 diagnostic criteria for schizophrenia

ICD-10 DIAGNOSTIC CRITERIA FOR SCHIZOPHRENIA

The normal requirement for a diagnosis of schizophrenia is that a minimum of one very clear symptom (and usually two or more if less clear-cut) belonging to any one of the groups listed below as (a) to (d), or symptoms from at least two of the groups referred to as (e) to (h), should have been clearly present for most of the time during a period of 1 month or more.

ASSOCIATED SYNDROMES, SYMPTOMS AND SIGNS

a) Thought echo, thought insertion or withdrawal, or thought broadcasting.

b) Delusions of control, influence or passivity, clearly referred to body or limb movements or specific thoughts, actions, or sensations; delusional perception.

c) Hallucinatory voices giving a running commentary on the patient's behaviour, or discussing him between themselves, or other types of hallucinatory voices coming from some part of the body.

d) Persistent delusions of other kinds that are culturally inappropriate and completely impossible (e.g. being able to control the weather, or being in communication with aliens from another world).

e) Persistent hallucinations in any modality, when occurring every day for at least one month, when accompanied by delusions (which may be fleeting or half-formed) without clear affective content, or when accompanied by persistent over-valued ideas.

f) Neologisms, breaks or interpolations in the train of thought, resulting in incoherence or irrelevant speech.

g) Catatonic behaviour, such as excitement, posturing or waxy flexibility, negativism, mutism and stupor.

h) Negative symptoms such as marked apathy, paucity of speech, and blunting or incongruity of emotional responses (it must be clear that these are not due to depression or to neuroleptic medication).

i) A significant and consistent change in the overall quality of some aspects of personal behaviour, manifest as loss of interest, aimlessness, idleness, a self-absorbed attitude, and social withdrawal.

(World Health Organisation 1993)

As can be seen in Table 3 and in Table 4, the DSM and ICD diagnostic criteria for schizophrenia are based upon what is thought to be clinically significant behavioural or psychological disturbance (Barker 2009b), and not evidence of physical causality, such as through physical testing such as blood analysis, scans or X-rays. The use of behavioural observations as a basis for illness diagnosis has been widely questioned and criticised for turning basic and fundamental behavioural and psychological problems of human living into pathological conditions (Barker 2009b; McGorry 1992; Porter 1987; Szasz 1988). An example of this is a social deficit that may result from the early environment in which one is raised but may instead be classified as a symptom of schizophrenia under a measure of functional impairment.

A psychiatric diagnosis can bring both benefits and costs to an individual receiving it, particularly the diagnosis of schizophrenia. Benefits are thought to include a sense of relief through knowing what is happening, and then being able to engage with appropriate support, resources and treatment (Robertson & Walter 2007). Costs can include distress, social isolation, difficulties in employment and the presence of a psychiatric diagnostic label meets the criteria for a person to be coercively detained and treated under Mental Health Legislation (Pilgrim 2007; Robertson & Walter 2007). Most powerfully, a mental illness diagnosis renders a person discreditable according to societal norms and leads to them being discredited within society and stigmatised as a result (Goffman 1968). Goffman wrote about stigma in the 1960s and it is still being discussed some 50 years later (Corrigan, Roe & Tsang 2011; Pilgrim 2007; Robertson & Walter 2007; Thornicroft et al. 2008; Wolff 2007).

The act of categorising a range of symptoms as an illness, and of prescribing treatment which is sometimes 'enforced' also pronounces the symptoms as abnormal or even harmfully dysfunctional and therefore undesirable (Robertson & Walter 2007). Labelling the illness as 'mental' invokes 'failure of the capacity for rational thought' (Robertson & Walter 2007, p. 793), renders the person 'discreditable', and reduces their power (Robertson & Walter 2007, p. 795). Social disadvantage is also a diagnostic partner (Robertson & Walter 2007). In research with people who have lived with schizophrenia, the feeling of being discredited and shamed within society is named as a consequence of the diagnostic process (Dinos et al. 2004; Vellenga & Christenson 1994).

Conversely, some research has identified benefits of receiving a diagnosis of schizophrenia such as feelings of relief at having the illness seen by someone [who knows, such as a clinician (Dinos et al. 2004; Vellenga & Christenson 1994), being able to name what has been happening, legitimising access to health care benefits, mobilisation of health care resources and the subsequent ability to receive correct treatment (Hayne 2003; Robertson & Walter 2007). Receiving the diagnosis can also be a catalyst for transforming present and future life expectations with relation to the illness experience (Bjorklund 1996). Hayne (2003) phenomenologically explored the experiences of 15 people named as mentally ill and identified four themes; diagnosis as the experience of a knowledge that knows, destructive (gift) of difference, making visible the invisible and making knowledge knowledgeable. These findings suggest that while it might be a relief to know, knowing also brings the beginnings of difference and the mantle of stigma. Being diagnosed is considered the benefit, rather than having the illness.

The costs of receiving a psychiatric diagnosis are associated with the devastation of the individual's identity (Hayne 2003) due to the perception of having a potentially chronic and disabling mental illness and the significant social consequences arising from the stigma of being discredited as mentally ill (Robertson & Walter 2007). Vellenga and Christenson (1994) identified deep losses attributed to the stigma of having a mental illness diagnosis and the feeling that society no longer sees the person; only the mental illness. These findings have been supported within other more recent consumer generated literature (Badesha 2002; Frese, Knight & Saks 2009; Romme & Morris 2007; Thornicroft et al. 2008). Empirical literature is replete with references to the 'schizophrenic person'; however studies of lived experience of schizophrenia reinforce that the illness and symptoms have nothing to do with the kind of person who has the illness (Chadwick 2007; Hayne 2003; Miller & Mason 2011). Therefore referring to 'people who have experienced schizophrenia' is far less stigmatising than 'schizophrenic persons' or 'schizophrenics' because it does not encompass the whole person within the diagnostic label.

Failure to diagnose is also regarded to be problematic and is associated with failure to treat, potential loss of productive work and impaired family functioning (Australian Government 2012). Diagnosis is important for individual reasons of knowledge and empowerment and yet is at the same time socially harmful for living in the world with the illness. There are well documented problems with the prevailing diagnostic classification systems however evidence shows that despite this, clinicians possess reliable, sensible and meaningful mental taxonomies to support their diagnosis and provision of treatment (Flanagan & Blashfield 2010; Flanagan, Keeley & Blashfield 2008).

Treatment approaches for schizophrenia

The most commonly used and dominant model of treatment in health care has traditionally been, and continues to be, the biomedical model (Dale & Melling 2006; Engel 1992; Millon 2004; Waltzer 1982). The biomedical model is also the dominant model of treatment within psychiatry and for schizophrenia (Beecher 2009; Bellack 2006; Beresford 2005; Bonney & Stickley 2008) with the focus being on control of symptoms, rather than cure (van Os & Kapur 2009).

Lewis, Lacasse and Spaulding-Givens (2010) examined conceptual, critical and theoretical literature on the medical model of mental illness to identify beliefs associated with the model. Their analysis identified three themes: 1) mental illness is a brain disease and is diagnosed and treated as such 2) mental illness is genetic and can be transmitted from one generation to the next and 3) the bizarre and deviant behaviour of people diagnosed with mental illness is irrational and beyond their control.

Many problems have been associated with adopting this model for the treatment of mental illness, for example, it does not consider the whole person and their attributes, nor the psychological or social nature of the person (Waltzer 1982). The person is instead reduced to a physio-chemical or biological entity in order to have meaning within the model (Waltzer 1982). The language used within the discipline is also disempowering and does not respect the individuality of the person (van Blarikom 2006), for example, as implied by the use of terms such as patient, ill, schizophrenic, disability, deficit and dysfunction (Beecher 2009; Rose et al. 2007).

Historically, treatments for schizophrenia were wide and varied but are not within the purview of this research. Suffice to say some, such as water dunking (Millon 2004), are now considered barbaric. The contemporary medical model uses three main approaches to delivering treatment for schizophrenia.

1)   Medications to relieve symptoms and to reduce the risk of relapse.

2)   Psychosocial interventions to educate on the illness, to develop skills to cope with the symptoms and to develop coping strategies with families.

3)   Rehabilitation services to achieve improvement in functioning in one major life domain, such as work relationships, housing or recreation.

(Anthony 1993; Rössler et al. 2005)

Whilst many of the abovementioned treatments are delivered within the medical model, the medical model of treatment also focuses on behavioural symptoms, the associated behavioural deficits and resulting dysfunction in the activities of daily living, as specified in the diagnostic criteria (Lieberman 1998, cited in Beecher 2009; Kelly & Gamble 2005; McCormack 2007; McCulloch et al. 2005; Romme & Morris 2007). This is regardless of the fact that these behavioural anomalies may not be a product of the illness but rather an environmental interaction that is consistent with the way the person is living their life rather than as a result of the illness (Romme & Morris 2007). The failure to properly assess the pre-existing level of functioning of the person can lead to the false opinion of failure to recover and labelling of the person as chronic and inducing a loss of hope, not only for the person but also for clinicians (McGorry 1992).

Clinician aspects

The term 'clinician's illusion' was coined by Cohen and Cohen (1984) to explain the phenomenon of clinicians believing that the person they are seeing during the illness episode is the way the person is all of the time, in all settings, not just the immediate treatment setting in which the encounter occurs.

Specialist mental health services operate on a supply and demand nature and unfortunately, demand far outstrips supply, forcing competition for services where the person with the greatest need or highest acuity gets priority and receives treatment (Adams, Daniels & Compagni 2009). Assessment by clinicians providing or seeking a portion of service for a client is therefore based on questioning what signs and symptoms, problems and deficits the person might have (McCormack 2007). Clinicians operating within the medical model of treatment become so accustomed to looking for symptoms, deficits and dysfunction to successfully access services for clients that it becomes the 'default' mode of thinking and defines the way treatment is offered (Beecher 2009; Romme & Morris 2007). As a result, Leggatt (2000) and Repper and Perkins (2003) suggest that clinicians experience little success or satisfaction in their work which exacerbates clinical pessimism. When coupled with the illness view inherent within the medical model, this twin cause for pessimism becomes a doubly strong impact.

A number of authors also suggest that clinicians experience a sense of powerlessness towards the schizophrenia diagnosis. Even though they think that the illness may improve with medication treatment they feel the person will never really be without symptoms of schizophrenia (Graybeal 2001). The clinician's sense of hopelessness and powerlessness about the diagnosis can be transferred to the person who has the

diagnosis (Leggatt 2000) and can cause clinicians albeit unknowingly to act prejudicially and through a lens of hopelessness towards people who have schizophrenia (Kelly & Gamble 2005).

Coupled with the clinician's illusion (Cohen & Cohen 1984) is the 'chronicity paradigm' whereby the qualities of chronicity are attributed to the disorder of schizophrenia itself, rather than , as a pre-existing attribute, a product of the health services or from community stigma (McGorry 1992; Ramon, Healy & Renouf 2007; Tooth et al. 2003).

A problem-focused and deficit-based view, which is arguably driven by diagnostic criteria, does not consider the whole person experiencing the problem and what skills, competencies and strengths they possess that may significantly enhance the healing process and bring about a more positive outcome (McCormack 2007). People diagnosed with schizophrenia do think about what has caused it and the decisions they are able to make about how they developed schizophrenia has a major impact on recovery (Charles, Manoranjitham & Jacob 2007; Corrigan, Kerr & Knudsen 2005) . The medical model does little to raise clients' awareness of their own contributory processes but regards them to be a passive recipient of the diagnosis and passive respondent to medication (Beecher 2009; Leggatt 2000). Such an approach can have a destructive impact on the person being diagnosed, 'forever harping on disasters, dangers, deficits and dysfunctions does not encourage the strength needed to overcome the problems that present themselves' (Chadwick 2009, p. 8) and can erode hope and the motivation to recover (Kylmä et al. 2006; Repper & Perkins 2003). A consequence from receiving treatment under the medical model, particularly when treatment is not successful, is that an individual can become stripped of their strengths, self-confidence and appropriately

assertive behaviour patterns to address the situation, resulting in a loss of hope, a weakened sense of competence and an increased sense of vulnerability to the inevitable outcome of medical treatment (Rapp & Goscha 2006).

For people who experience schizophrenia, a hopeful view is correlated with positive health outcomes, symptom reduction and development of a future orientation (Harding et al. 1987; Kylmä et al. 2006; McGrath et al. 2009; Miller & Mason 2011). A sense of hope can support a person to take risks and to get back up again and have another go when an attempt fails (Kelly & Gamble 2005; Kylmä et al. 2006). 'Hope connects someone directly to the dreamed-of future' (Peterson & Seligman 2004, p. 519). Being seen as an individual, with strengths and capacity to love and find meaning and not defined as a set of symptoms, a disease or illness or a 'schizophrenic' is important (Kelly & Gamble 2005). People who support others through believing and giving hope are supporting recovery (Ralph & Corrigan 2005), and therefore this is an essential attitude for a clinician to hold (Moxham, Robson & Pegg 2012).

Some people with schizophrenia have suggested that health professionals generate experiences of hopelessness and helplessness through excluding them in the planning and treatment process and strictly adhering to the medication and monitoring practices of the medical model. Stripping hope from a person through negative clinical language can lead to learned hopelessness (May 2000), and consequently, people with a diagnosis of schizophrenia have been disempowered, marginalised and oppressed (Barker 2009a; McLean 1990; Pearson & Gerzon 2001).

In most countries, the 'state' licenses and invests power in clinicians to have the right to treat mental illness. McLean (1990) and Szasz (2008) argue that service users need to

contribute to the expression of that power to counter-balance the systematised oppression. The opportunity to contribute came about through the emergent voices of educated, successful people who also had a mental illness diagnosis and who held significantly powerful or influential positions in society, such as practicing psychiatrists, psychologists, sociologists, professors, lawyers, and people holding a government office (Frese, Knight & Saks 2009). The rally for consumer inclusion occurred in Australia, with significant people speaking out, such as government ministers, for example, Jeff Kennett, former Premier of the state of Victoria, John Brogden, former leader of the opposition in the state of New South Wales and several high profile media personalities and celebrities, such as sports broadcaster Craig Hamilton and news reader Jessica Rowe (Brogden 2009; Hamilton & Jameson 2004; Kennett 2005; 2007; McGrath et al. 2009).

Unlike the majority of disempowered products of the mental health system (Pitt et al. 2009), these empowered people began to publish accounts of their experiences and opinions and they presented a different perspective to the published views of the professionals and researchers (Frese, Knight & Saks 2009). They advocated for themselves and others who experience mental illness and demanded their own perspective be considered in the creation of the knowledge informing development of mental health policy, planning and delivery of health services and treatment models (Frese, Knight & Saks 2009). People with lived experience argued for the right to be treated as human beings, rather than as a diagnosis or a case to be managed, for the right to receive factual information and have a say in their treatment, for the stigmatised view of the community to be changed and for the right to conduct support and advocacy groups as service users (Beales et al. 2008; Chamberlin 1978; Cohen & Cohen 1984;

Corrigan, Roe & Tsang 2011; Del Vecchio 2006; Epstein & Olsen 1998; Morrison 2003; Thornicroft et al. 2008).

Living with schizophrenia

Multiple longitudinal studies found that the majority of people with schizophrenia achieve a good outcome (Bleuler 1978; Ciompi 1980; Harding et al. 1987; Harrow et al. 2005; Lambert et al. 2008; Levine et al. 2011; Mason et al. 1996; Rabinowitz et al. 2007; Robinson et al. 2004; Strauss et al. 2010). Hegarty et al (1994) conducted a meta-analysis of 821 studies covering 100 years of outcome data related to schizophrenia (1895 – 1992) and identified improvement in 40.2 per cent of people at an average follow up point of 5.6 years. The terms *good outcome* and *improved* included the following results from the longitudinal studies reviewed; recovered, in remission, well without residual symptoms, minimally or mildly symptomatic, improved without significant deficit, socially recovered, or working or living independently (Bleuler 1978; Ciompi 1980; Harding et al. 1987; Harrow et al. 2005; Hegarty et al. 1994, p. 1410; Lambert et al. 2008; Levine et al. 2011; Mason et al. 1996; Rabinowitz et al. 2007; Robinson et al. 2004; Strauss et al. 2010).

There may be a number of reasons why the 'evidence' supporting the fact that schizophrenia is not the one-way journey to dementia for all as originally suggested by Kraepelin (Berrios & Hauser 1988; Kapur 2011), did not translate as a fundamental premise of clinical practice. Longitudinal studies identifying good outcomes have been conducted across such a diverse range of countries, populations, participants and research methodologies that they are difficult to compare except for the one consistent message that the majority, but not all, people experience good outcomes (Liberman et al. 2002). Direct comparison between studies is difficult and generalisation even harder

to make due to the diversity of methodologies, the selection criteria used to include people in the studies and the operational criteria used to measure their progress or long-term outcomes (Liberman et al. 2002). Despite these methodological differences, findings of good outcome have been consistently demonstrated across research, across countries, and across more than a century.

In 2002 the then United States of America President George W. Bush commissioned a comprehensive review and report on the American mental health service delivery system to underpin reform of policies including the reduction of inequality towards people with serious mental illness and disability (President's New Freedom Commission on Mental Health 2003). The resulting New Freedom Commission Report on Mental Health (2003, p. 1) called for the transformation of the North American 'mental health services and supports [to] actively facilitate recovery and build resilience to face life's challenges'. The Commission found that recovery from mental illness is now a real possibility (President's New Freedom Commission on Mental Health 2003), despite research-based evidence of this having existed for the previous one hundred years. As part of the transformative process, the involvement of service users and families was mandated, particularly with regard to addressing the disempowerment, marginalisation and oppression of people diagnosed with a mental illness (Frese, Knight & Saks 2009). A similar call for a recovery orientation and the building of resilience appeared in the 2003 Australian National Mental Health Plan (Australian Health Ministers 2003) and continues in later plans (Commonwealth of Australia 2008; 2009). The words *recovery* and *resilience* did not appear in any part of the previous 1992 Australian National Mental Health Plan (Australian Health Ministers 1992).

The transformation of mental health service delivery systems to adopt a recovery orientation and to facilitate building resilience was nothing short of a paradigm shift, which in a mature science, is defined as a transition from one paradigm to another via a 'revolution' (Kuhn 1996). Covey (1990) defines a paradigm as the map in a person's mind that determines the way they see the world. In this case, the 'revolution' was brought about by the revolt of past in-patients of psychiatric institutions, who began to publish accounts of their experiences and opinions which presented a different perspective to the published views of the professionals and scientific researchers (Crossley & Crossley 2001; Frese, Knight & Saks 2009). Although using the term 'paradigm shift' to refer to the philosophical and practical change that swept psychiatry does not entirely conform to Kuhn's positivistic model of a revolution within scientific thought, the elements of a build-up of anomalies against a current paradigm, sufficient to bring about a crisis that results in a shift towards a new paradigm or worldview are certainly present (Crossley & Crossley 2001; Glover 2005).

Some of the unacceptable and appalling aspects of coercive institutional care had been topics of discussion and debate for as long as this type of treatment existed. However events such as de-institutionalisation, and the advocacy of empowered survivors of the system, have been credited with bringing about the paradigm shift (Crossley & Crossley 2001; Frese, Walker & Davis 1997).

Survivors advocated for themselves and demanded their own perspective be considered in the creation of the knowledge informing development of mental health policy, planning and delivery of health services and treatment models (Chadwick 1997; Crossley 1999; Frese, Knight & Saks 2009).

An important part of the paradigm shift for some health professionals and researchers is a move away from the dominant focus on illness, disease, psychopathology, risk, vulnerability, deficits, damage and weakness to include focussing on the person and their health, strengths, potential, empowerment, partnership, protection and well-being (Manderscheid et al. 2010; McCormack 2007).

A review of British literature was carried out by Bonney and Stickley (2008) to explore perspectives of service users, health care providers and policy makers on changes that should be made within the emerging paradigm. Six broad and recurrent themes emerged;

1)   IDENTITY: The need for individuals to redefine their identity and accept themselves anew,

2)   SERVICE PROVISION AGENDA: For services to realise that recovery is not about cure and people often need to recover from the effects of the system in which they are treated,

3)   THE SOCIAL DOMAIN: People need to be a de-stigmatised and valued member of mainstream society and have equality of access to opportunity and services,

4)   POWER AND CONTROL: People should be included in decision making and have services shaped around their personal needs as determined by them,

5)   HOPE AND OPTIMISM: Staff should be 'holders of hope' and maintain an optimistic view, and

6)   RISK AND RESPONSIBILITY: Enabling risk taking to achieve change avoids fostering dependence.

(Bonney & Stickley 2008, pp. 141-149)

In the USA in 2004, the Substance Abuse and Mental Health Services Administration convened a National Consensus Conference on Mental Health Recovery for the purpose of bringing together mental health consumers, family members, providers, advocates, researchers, academics, accredited organisation representatives, managed care representatives, state and local public officials and others to create a consensus definition of recovery. The following statement for a consensus definition was issued as a result:

> *Mental health recovery is a journey of healing and transformation and living a full and meaningful life in a place of one's own choice while striving to achieve one's own full potential.*

(Substance Abuse and Mental Health Services Administration 2004, p. 1)

Whilst there is an increasing body of research from the 1990s to the present time addressing the realities of adopting a recovery orientation within mental health service delivery, very little is known about the meaning of resilience in the context of mental illness, despite it being an important focus within this 'new approach' (Australian Health Ministers 2003; Commonwealth of Australia 2009; Friedli 2009; President's New Freedom Commission on Mental Health 2003).

A state of mental health is a component of resilience (Friedli 2009; Harrison 2004; Keyes 2005) and leads to healthier lifestyles, better physical health, improved recovery, fewer limitations in activities of daily living, higher educational attainment, greater productivity, employment and earnings, better relationships, greater social cohesion and engagement and improved quality of life (World Health Organisation 2004). In 2009, the World Health Organisation declared that resilience building should be included in mental health service delivery approaches (Friedli 2009). Within Australia, since 2003, research has been called for to understand and promote building of people's resilience

for dealing with mental health problems and for reducing risks for mental health problems and the development of mental illness (Australian Health Ministers 2003).

Schizophrenia is a mental illness characterised by undesirable schisms between mood, thought and behaviour that interfere with daily functioning. No two people diagnosed with schizophrenia will experience the same mix of symptoms in the same pattern; there is a high degree of variability. The cause is unknown and development of the illness is understood to result from the interplay of both genetics and the social environment. Equal numbers of males and females are affected and there are differences in prevalence between developing and developed nations and the reasons for this are unclear. Schizophrenia has a high cost both financially and in terms of burden for those who develop it and their families and the greater society in which they live. The most serious burden is the increased risk of suicide over that of the general population.

Receiving a diagnosis of schizophrenia can be both a stigmatising burden and also a welcome relief. Having a label of schizophrenia exposes the person to being judged, discredited and disempowered through being placed in a sick role under which involuntary treatment is possible, however being able to understand what is happening and being able to access appropriate treatment and support is crucial. Prescribing medication to control symptoms has historically been the main treatment focus however this has now broadened out into a more person-centred approach that includes medications but also includes the recovery of the person within their greater life context.

The majority of people live a fulfilling life with schizophrenia, a smaller percentage live with varying levels of symptoms and the remainder live with a level of symptoms that have a daily impact on their ability to function in the usual activities of daily living.

Section two: Resilience

Little is known about the relationship between resilience and mental illness and literature is largely silent on resilience in this context, particularly with regard to what resilience is, how it is developed and what the relationship between mental illness and resilience might be. The inclusion of resilience in the national mental health planning of both Australia and the United States of America was for the purpose of increasing the ability of people who experience mental illness to be able to cope with life stressors, to support recovery, to improve quality of life and to support growth (Australian Health Ministers 2003; President's New Freedom Commission on Mental Health 2003).

Definitions of resilience

The origin of the word 'resilient' is Latin and means 'leaping back' (Davidson et al. 2007). Historically, resilience is a word used in materials science to describe the elastic property of a material under strain that allows it to return to its normal state when the strain is removed (Baumeister, Avallone & Sadegh 2007).   Both of these definitions suggest a return to original form following stress; however, the term resilience when used within the study of human behaviour, has many different meanings;

> *Researchers, policymakers and practitioners have long succeeded in making English words such as health and resilience mean just what they choose them to mean, depending on their academic discipline, political allegiance, and/or personal moral convictions – or in deed any combination of these factors.*

(Almedon & Glandon 2007, p. 127)

Therefore, prior to evaluating resilience literature and research findings it is important to consider the meanings on which this research has been predicated. Table 5 provides some quoted definitions and some summarised meanings for resilience from the literature reviewed.

Table 5: Resilience within the study of human behaviour

RESILIENCE WITHIN THE STUDY OF HUMAN BEHAVIOUR	
Resilience is an interactive concept that refers to a relative resistance to environmental risk experiences, or the overcoming of stress or adversity.	Rutter 2006b, p. 1
Resilience is the ability to maintain a stable equilibrium with the capacity for generative experiences and positive emotions.	Bonanno 200
Resilience is demonstrating competence despite the ongoing presence of a stressor.	Glantz & Johnson 1999
Positive elements within the individual and external environments that lead to an adaptive outcome.	Garmezy 1971
Efforts to restore or maintain internal or external equilibrium under significant threat.	Masten, Best & Garmezy 1991, p. 430
The ability to transform disaster into a growth experience and move forward.	Polk 1997, p. 1
Resilience is common and ordinary [.....] usually arises from the normative functions of human adaptational systems.	Masten 2001, p. 227
Good outcome despite serious threats to adaptation or development.	Masten, Best & Garmezy 1991
A fluid process of adapting and prospering in the face of stress, which evolves over time and is influenced by context.	Becvar 2007
Bounce back, cope successfully, and function above the norm in spite of significant stress or adversity.	Tusaie & Dyer 2004, p. 3
Thriving in the face of adversity.	Connor & Davidson 2003
Good developmental outcomes and sustained competence despite the presence of stress and risk.	Werner 1995
Dealing with disruptive, stressful or challenging life events in a way that provides additional protective and coping skills than prior to the disruption.	Richardson et al 2002
Phenomenon or process reflecting relatively positive adaptation (despite) experiences of significant adversity or trauma.	Luthar 2006, p. 742
Successful adaptation despite risk and adversity.	Masten 1995
Responding to stressful events through regaining equilibrium and growing healthily.	Reich, Zautra & Hall 2010
Stability, quick recovery, or even growth under significant adverse conditions.	Leipold & Greve 2009

The definitions presented in Table 5 indicate that resilience within human behaviour is an individual phenomenon that is related to the ability to adapt or respond to a serious stressor that significantly challenges the person. Although there is some degree of homogeneity there are also differences within the definitions. Some researchers see the person as maintaining equilibrium in the face of the stressor, that is, they do not break down under the stress (Bonanno 2004; Connor & Davidson 2003; Garmezy 1971; Glantz & Johnson 1999; Rutter 2006b; Werner 1995) while others indicate that the person may decompensate (Polk 2000; Reich, Zautra & Hall 2010; Richardson 2011; Tusaie & Dyer 2004).

Masten (2007) has more recently viewed resilience as the capacity of a dynamic system to recover from and also to resist or withstand significant disturbances. Masten's definition encompasses both definitions; *resisting or withstanding* and *recovering from*. *Resisting or withstanding* may assume the presence of competence prior to the challenge occurring and *recovering from* may refer to the outcome of a challenge and suggest that decompensation occurs, which is then recovered from (Masten 2007). Patterson (2002a; 2002b) defines the term *resiliency* as having the capacity to respond resiliently and defines *resilience* as specific processes which emerge in response to significant stress.

Additionally some definitions of resilience include a personal growth outcome as a result of gaining additional resources or new coping skills during the experience of adversity (Luthar, Sawyer & Brown 2006; Polk 1997; Reich, Zautra & Hall 2010; Richardson 2002; Tusaie & Dyer 2004). Other definitions have found a way to encompass all criteria, such as that posited by Leipold and Grieve (2009, p. 41) who suggest that resilience is 'an individual's stability or quick recovery (or even growth)

under significant adverse conditions'. All definitions in Table 5 include the presence of a significant threat to functioning and therefore this is considered an essential criteria for the definition of resilience (Masten & Obradovic 2006).

Researchers have also suggested that resilience is context specific (Connor & Davidson 2003; Luthar & Cicchetti 2000; Masten 2001) and that individuals may demonstrate resilience in the face of some challenges and not others (Rutter 1999b; 2006b). Furthermore, even a resilient person may decompensate if the stress goes on for too long (Wald et al. 2006). Masten and Obradovic (2006) found that resilience means something different culturally, developmentally and historically.   The emerging diversity of factors associated with resilience indicates that resilience is highly contextual and that resilience means whatever researchers define it as meaning when designing and applying their research methodology (Luthar 2006; Obradovic, Burt & Masten 2006; Rutter 2006b).

Understanding resilience

Inquiry on resilience is said to have occurred in three waves which are ongoing;

1)   identification and description of the phenomena,

2)   exploration of the process, and

3)   research into how it may be manipulated.

(Richardson 2002)

Furthermore, a fourth wave of inquiry is now emerging in the literature, which is concerned with linking biology and neuroscience to behavioural adaptation in development (Masten & Obradovic 2006; Richardson 2011).

In the first wave, resilience was recognised within the study of children (Werner 1989) raised in severely adverse rearing circumstances who nonetheless emerged as competent adults. A *competent adult* was defined as a person who had no psychiatric diagnoses or co-morbid substance use disorders and who lead a functional life (Erlenmeyer-Kimling et al. 1984; Garmezy & Devine 1984; Mednick et al. 1984; Rodnick et al. 1984; Weintraub & Neale 1984; Worland et al. 1984; Wynne 1984). First wave resilience research identified individual characteristics of resilience. Table 6 presents examples of personal qualities associated with resilient responses in the face of severe adversity (adapted from a review of resilience literature by Wald et al 2006).

Table 6: Personal qualities associated with resilience

PERSONAL QUALITIES	AUTHOR
Achievement oriented	Werner 1982, 1989; Werner & Smith 1992
Action oriented approach	Rutter 1985
Adaptability to change	Block & Block 1980; Bonanno et al. 2004; Dumont & Provost 1999; Frederickson et al. 2001; Rutter 1985; Werner 1982, 1989; Werner & Smith 1992
Being cuddly & affectionate in infancy	Radke-Yarrow & Sherman 1990; Werner 1989
Capacity for positive emotional expression	Bonanno 2004; Fredrickson et al. 2003; Tugade & Fredrickson 2004; Tugade et al. 2004; Zautra et al. 2005
Capacity to construct productive meaning	Beardslee 1989; Rutter 1990
Creativity	Simonton 2000
Critical thinking skills	Garmezy 1985, 1987, 1991; Garmezy et al. 1984
Ego-resiliency and ego-control	Cicchetti & Rogosch 1997; Flores et al 2005
Flexibility	Dumont & Provost 1999; Frederickson et al. 2001

PERSONAL QUALITIES	AUTHOR
Higher intellectual functioning	Curtis & Cicchetti 2003; Garmezy 1985, 1987, 1991; Garmezy et al. 1984; Masten et al. 1988, 1998, 1999
Internal locus of control	Garmezy 1985, 1987, 1991; Garmezy et al. 1984; Luthar 1991; Werner 1982, 1989; Werner & Smith 1992
Low avoidance or distraction strategies	Bonanno, Wortman & Nesse 2004
Openness to experience	Affleck & Tennen 1996; Tedeschi & Calhoun 1996, 2004; Tedeschi et al. 1998
Optimism	Affleck & Tennen 1996; Connor & Davidson 2003; Garmezy 1985, 1987, 1991; Garmezy et al. 1984; Kumpfer 1999; Masten & Reed 2002; Peterson 2000
Patience	Lyons 1991
Positive acceptance of change	Connor & Davidson 2003
Problem solving skills	Garmezy 1985, 1987, 1991; Garmezy et al. 1984
Recognition of limits to control	Connor & Davidson 2003; Kobasa 1979; Rutter 1985
Robust	Werner 1982, 1989; Werner & Smith 1992
Self-determination	Ryan & Deci 2000; Schwartz 2000
Self-discipline	Garmezy 1985, 1987, 1991; Garmezy et al. 1984
Self-efficacy	Connor & Davidson 2003; Rutter 1985
Sense of humour	Garmezy 1985, 1987, 1991; Garmezy et al. 1984; Masten & Reed 2002; Rutter 1985
Socially responsible	Werner 1982, 1989; Werner & Smith 1992
Tolerance of negative affect	Connor & Davidson 2003; Lyons 1991; Werner 1982, 1989; Werner & Smith 1992
Trust in one's instincts	Connor & Davidson 2003
View change or stress as a challenge or opportunity	Kobasa 1979
Wisdom	Baltes & Staudinger 2000

The second wave of resilience inquiry focused on the process of resilience. People who were identified as resilient in the first wave studies may have had particular personal qualities, but the process in which these qualities were called into play needed to be understood. The second wave of inquiry is ongoing (Masten & Obradovic 2006) however within this, several descriptions of a process for resilience have been advanced.

In Polk's model of resilience, adversity provides an energy that temporarily creates a disorganising experience which disrupts functioning and forces change to a higher level of organisation (Polk 2000). During the disruption, both internal and external resources are used to ameliorate the risks posed by the adversity and to bring about and maintain the positive response (Luthar 2006; Luthar & Cicchetti 2000; Rutter 1990).

Internal resources include many of the personal qualities listed in Table 6, for example being achievement orientated, being adaptable to change and having the capacity for positive emotional expression (Bonanno 2004; Rutter 1985; Werner 1995). External resources are associated with the environment, for example; the availability of emerging opportunities, finding a mentor, finding a faith, leaving a deviant peer group or otherwise taking an action that brings about a positive consequence (Masten 2001).

Internal and external resources are viewed positively and are regarded to be protective against risk (Masten et al. 1999). There are though, factors associated with creating risk which are connected with adverse experiences. These factors may be internal to the person experiencing the strain or be associated with the environment in which the experience takes place (Masten et al. 1999). Also important are the type, number and frequency of risk factors involved. Statistical predictors of high risk and situations which contribute to negative developmental outcome include; exposure to maltreatment

or violence, having a parent with schizophrenia, low socioeconomic status, massive community trauma (Masten 2001; Rak & Patterson 1996; Rutter 1999a; Werner 1989; Werner & Smith 2001), poverty, daily instability, perinatal stress, low birth weight (Werner 1989; Werner & Smith 2001), parental criminality, placement in care (Rak & Patterson 1996; Rutter 1999b) and parental loss and divorce (Rutter 1999b).

The positive qualities of the person, the protective factors within the person's environment and the reduction of recognised risks combine to promote a resilient response (Masten et al. 1999). Successfully engaging with low levels of risk creates a *steeling effect,* which, according to Rutter (1985, 1987), in turn enhances coping and builds protection. If the level of risk grows, the outcome normally associated with the risk will occur (Werner 1989). If an individual has not been challenged they may be more vulnerable than someone who has developed the previously discussed steeling effect from experiencing low level risk (Wolin & Wolin 1995). However, with regard to protective resources, their presence is not enough to guarantee that an individual will react to adverse and stressful situations with resilience.

Different protective resources have different main effect associations with a resilient response. For example experiencing a caring, supportive relationship has a higher correlation with resilient response than having high socioeconomic status (Luthar 2006). Another example is having a competent older sibling, which was found to build competence in younger siblings, however only when the younger sibling also possessed the quality of self-regulation (Brody 2004). Intimate and caring relationships are one protective resource found to uniquely predict a resilient outcome (Shonkoff & Phillips 2000). Garmezy, Masten and Tellegen (1984) developed a resiliency triad which includes personality disposition (such as possessing some of the personality factors

described in Table 6), having a supportive family environment (a family environment which is not characteristic of the loaded environment which was discussed within chapter two, section one), and having an external support system (such as a peer network or community relationships).

Masten (2001) introduces the concept of a *risk gradient* when assessing the situation in which the protective factors will be drawn upon to affect the amount of strain resulting from stress. According to Masten (2009), accumulation of negative risk factors at a particular point in time is strongly correlated to rising risk for poor outcome in multiple developmental areas, such as physical health, social competence and mental health. Masten (2001) also discusses the existence of an *asset* or *resource* gradient of internal and external protective factors which offsets the risk gradient (see Figure 2). The number and types of protective factors are listed as assets or resources and are called 'bipolar predictors' because they can predict the potential for positive or negative outcome according to their loading. This leads to the possibility of the manipulation of factors to push the outcome in a positive direction.
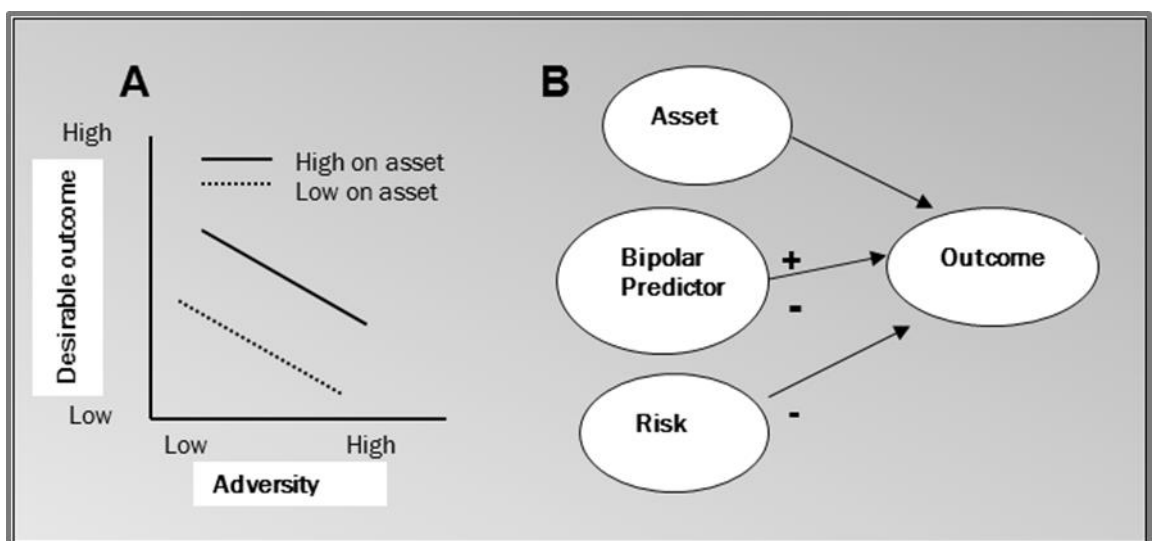
(Masten 2001)

Figure 2: Multivariate analysis in resilience

In Masten's findings, multiple risk factors (bipolar predictors) are associated with poor outcome when faced with a low number of protective factors (assets). Multiple positive protective factors are associated with a positive outcome when faced with a surmountable number of risk factors. However, Masten (2001) is also careful to point out that there are pure risk factors which are likely to result in negative outcomes due to the strength of their individual effect, such as a serious motor vehicle accident causing a negative outcome. Likewise, there are factors that are viewed as purely protective, such as having a prodigious talent which causes a positive outcome.

The dynamic of protective factors being compensatory in the face of risk is not sufficient to explain resilience. The specific underlying influential processes need to be understood also (Luthar 2006). The 'Resiliency Model' presented in Figure 3 and developed by Richardson, Neiger, Jensen and Kumpfer (Richardson 2002; Richardson et al. 1990) describes a 'simple' linear resilience process, with four potential outcomes, during which a person experiences stressful or adverse life events which disrupt their mind, body and spirit (termed 'biopsychospiritual homeostasis'), resulting in a disrupted state (Richardson 2002; Richardson et al. 1990). While in the disrupted state, the person acts to invoke protective resources to ameliorate the threat posed by the stress or adversity. The person then moves from the disrupted state into a reintegrated state of physical, mental and spiritual homeostasis. Richardson's model of resilience (Richardson et al. 1990), presented in Figure 3 categorises a range of possible outcomes from facing adversity, whereas Masten's model of resilience (Masten 2001), shown earlier in Figure 2 only mentions outcome as a single category and focusses more on the dynamic within the relationship between resilience and adversity.
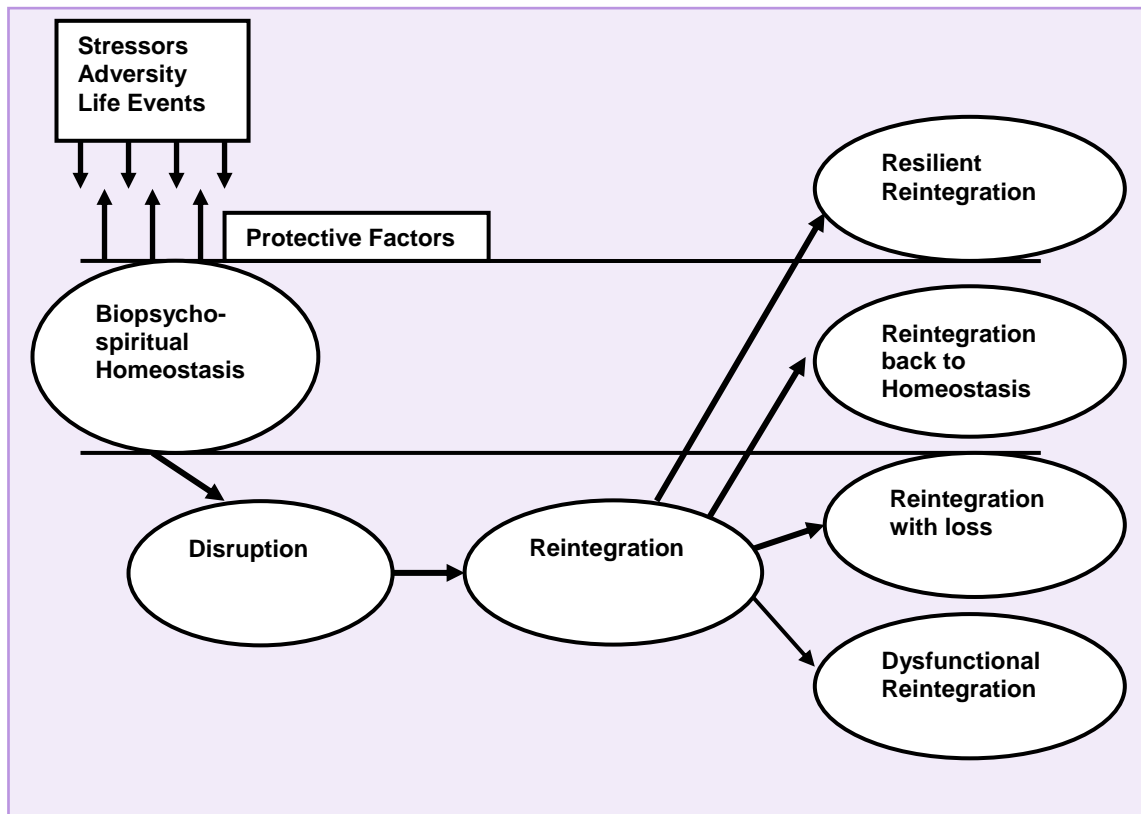
Figure 3: The Resiliency Model 1990

The outcome of reintegration may be dependent upon the level of disruption and the availability of protective and risk variables, both internal and external, which can be operationalised consciously or unconsciously by an individual (Richardson 2002; Richardson et al. 1990). The person can reintegrate with *improved function* (resilient reintegration), *maintained function* (return to homeostasis), *loss of function* (reintegration with loss) or *dysfunction* (dysfunctional reintegration) (Richardson 2002; Richardson et al. 1990). A resilient response requires reintegration with *improved function*, not a return to homeostasis.

A previous encounter with the same or similar situation is likely to result in a reintegration to homeostasis or an improvement in function (resilient reintegration) because the person has had previous experience and has developed knowledge and skills

on how to manage the situation (increased strength of resilient qualities). Reintegration to homeostasis is also called the comfort zone which is return to a previous state. Reintegration with loss involves giving up something, such as giving up hope, feeling pessimistic and losing motivation to tackle the challenge. Dysfunctional reintegration may include using substances or carrying out destructive behaviour in an attempt to reduce the discomfort caused by the challenge or adversity. Stressors may take minutes or years to resolve or there may be multiple disruptions concurrently (Richardson 2002).

Several authors and researchers have referred to challenge as an important precursor to growth and several models of challenge have been developed (Badesha 2002; Hollister-Wagner, Foshee & Jackson 2001; O'Leary & Ickovics 1995; Waibel, Yarnell & Whitehouse 2011; Walsh 1994; Wolin & Wolin 1995). Under the Challenge Model (Badesha 2002), moderate stress and risk are seen as opportunities to enhance successful adaptation and strengthen competence. Too little is regarded as not enough of a challenge while too much runs the risk of being overwhelming. Successfully dealing with stress and risk within a situation develops resiliency for future exposure to that same situation (Badesha 2002; Masten et al. 1999; Rutter 1987).

Wolin and Wolin (1995) studied children of families seriously troubled by substance misuse, and in particular the children within those families who had successfully mastered adversity. Wolin and Wolin (1995) based their Challenge Model on the proposition that low levels of risk stimulate the person's use of protective resources, which if followed by successful coping, strengthens and stimulates protection (Hollister-Wagner, Foshee & Jackson 2001). Protective factors then prevent the expression of negative outcome despite the exposure to risk. The Challenge Model also refers to this as the steeling effect (Hollister-Wagner, Foshee & Jackson 2001; Waibel,

Yarnell & Whitehouse 2011; Walsh 1994; Wolin & Wolin 1995). Wolin and Wolin (1995) assert that protective factors have a profound effect on a person's life course and help to develop the steeling effect, which in turn allows tolerance of deviation from ideal circumstances and contributes to the development of self-righting tendencies. Engaging in this type of coping makes individuals experts in their own healing (Hollister-Wagner, Foshee & Jackson 2001; Walsh 1994; Wolin & Wolin 1995).

O'Leary and Ickovics (1995) conceptualise that challenge provides an opportunity for an individual to succumb or respond and that there are three potential outcomes; survival, recovery or thriving. Survival is associated with an outcome that demonstrates impaired function, whereas recovery is associated with a return to the baseline of previous function and thriving is associated with resilience, and is demonstrated by an outcome of growth and flourishing. Figure 4 illustrates O'Leary and Ickovics (1995) model which assumes a single hypothetical stressor over time:
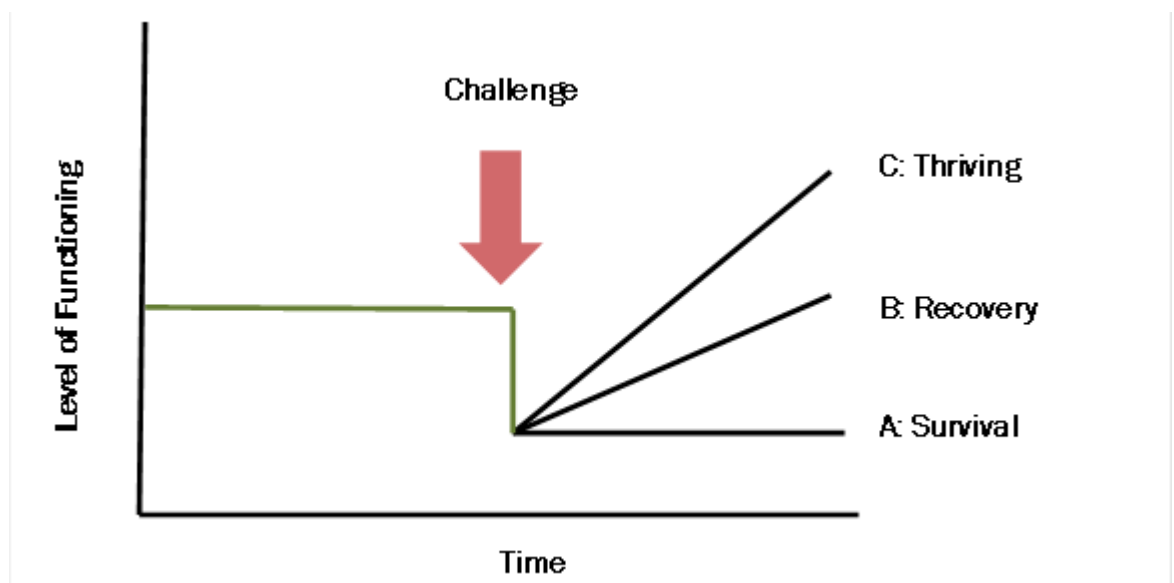
(O'Leary & Ickovics 1995)

Figure 4: Outcomes of challenge

Richardson considered how resilience develops from the perspective of the person and how unlocking what he believes to be innate resilience during the experience of adversity subsequently achieves resilient reintegration. Other resilience theorists also find resilience to be naturally occurring (Garmezy & Devine 1984; Masten 2007; Richardson 2011; Staudinger, Marsiske & Baltes 1995). Richardson's original Resiliency Model (Richardson et al. 1990), (Figure 3) has been reconceptualised as a more fluid process which includes the unlocking of natural resilience drives within the stage of resilient reintegration and also longer includes dysfunctional reintegration as an outcome. Richardson's revised Resilience Model (Richardson 2011) is presented in Figure 5.

RESILIENCY MAPPING

Resilient Prompts/ Life Events

Comfort Zone

Disruption

Reintegration

Resilient Reintegration

Reintegration Back to the Comfort Zone

Resonation Quickening

Reintegration with Loss
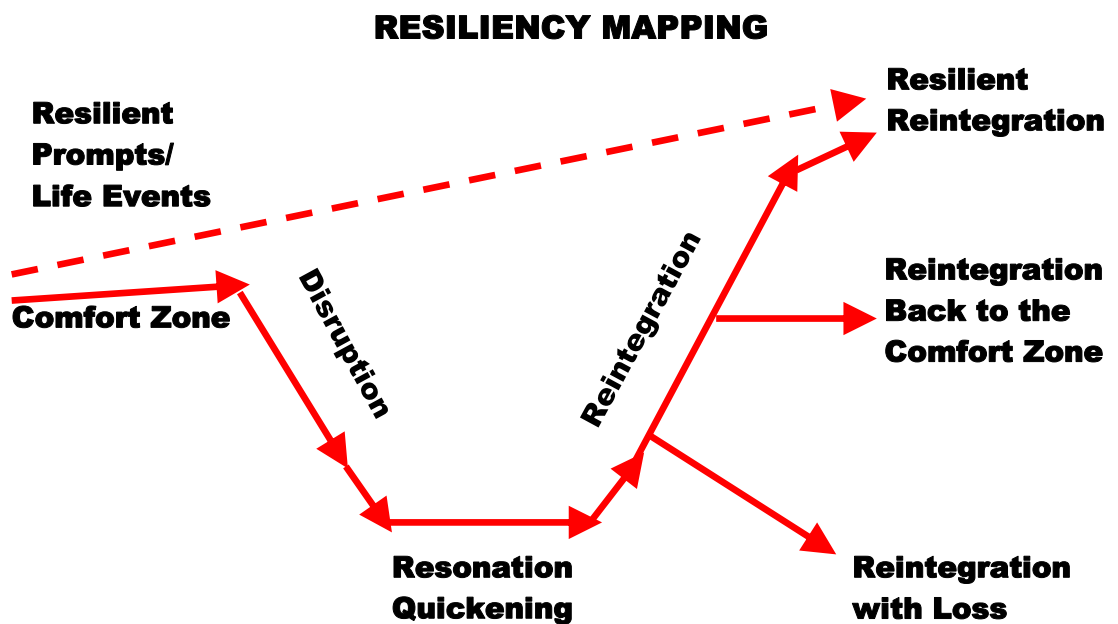
(Richardson 2011)

Figure 5: The Resiliency Model 2011

Experiences of *resonation and quickening* have been identified between the previous stages of disruption and reintegration (see Figure 3). Resonation is an act of searching

for feedback that will enrich the persons understanding or facilitate coping in some way and quickening is experiencing a transformation or turning point as a result of the resonant search. The experience of resonation and quickening is hypothesised to be essential to discovering and stimulating the resilient drives within. Examples of activities associated with achieving resonation are; journal writing, reminiscence, praying, meditating and pondering dreams. Examples of the ways in which a person may feel *quickening* include bursts of understanding, confirmations of truth, an awareness of guidance, moments of enlightenment and inspiration, renewed hope and optimism, triumph of courage over fear, sensing a new identity, sensing power beyond the self, feeling the drive of purpose, feeling healed and feeling motivated. These factors are associated with achieving a resilient outcome (Richardson 2011).

Rutter (2006b) summarised what has been learned through the three different waves of resilience inquiry. These are presented in Table 7.

Table 7: Implications of resilience for scientific understanding

IMPLICATIONS OF RESILIENCE FOR SCIENTIFIC UNDERSTANDING
1. Resilience as a resistance to hazards may come from controlled exposure to risk rather than avoiding it.
2. Resistance may come from traits or circumstances that exhibit little effect when hazards are not present.
3. Resistance may come from physiological or psychological coping rather than the presence of protective factors or the management of risk.
4. Delayed recovery may come from 'turning point' experiences.
5. Resilience may be constrained by biological factors or the damaging effects of stress and adversity on neural structures.

(Rutter 2006b)

Whilst the importance of resilience as an approach to overcoming the severe adversity of mental illness is promoted, the relationship between resilience and schizophrenia is little researched and poorly understood. Many definitions of resilience exist and most include an individual's ability to adapt in the face of a serious stressor or severe adversity and to emerge in an improved state. An improved state includes having developed additional strength or resources with which to face future challenges and this is seen as growth. Resilience is an energy that is used within a process and leads to the specific outcomes of overcoming adversity and growing.

Section three describes what is known of resilience in the context of schizophrenia.

Section three: Resilience and schizophrenia

Each person who experiences schizophrenia has their own individual pathway of problems, deficits and experiences and their own risk factors and protective resources arising from their own unique situation.   Furthermore, resilience has also been hypothesised to be not only an attribute of individual people but also an attribute of the systems surrounding individuals (Hanson & Gottesman 2012) and therefore vulnerability might not come as a result of failure of an individual's resilience but the systems around them.   Schizophrenia presents different challenges to each individual who experiences it and in response; individuals will use different coping strategies, skills, strengths and systems in the face of the challenges.   The function of resilience within this mix of factors is also unique and needs to be studied in context to understand the role and dynamic resilience takes against schizophrenia-related problems.   This thesis therefore contributes to such an understanding.

A relationship between stress, vulnerability and schizophrenia was established in the 1970s (Zubin & Spring 1977) and remains valid (Gispen-de Wied & Jansen 2002; Keshavan et al. 2008b; Masten et al. 1999; Resch 2002; Schore 2003; Waddington & Scully 2002).   A serious stressor for a person who is considered to be genetically vulnerable to schizophrenia can result in the person developing a psychotic state, which is a criteria for the diagnosis of schizophrenia (Garmezy 1971; 1993; Gispen-de Wied & Jansen 2002; Keshavan et al. 2008b; Zubin & Spring 1977).   In contrast, a resilient response to a serious stressor could be to adapt, overcome the stressor and grow in some way from the experience, for example by developing additional resources.   By decompensating into a psychotic state, the person is demonstrating vulnerability rather than resilience to this particular challenge.   Therefore, people who have experienced

many episodes of psychosis and have been diagnosed with schizophrenia are regarded to be vulnerable to the challenges of schizophrenia, rather than resilient, which requires demonstration of 'a stable trajectory of healthy functioning across time' (Bonanno 2004, p. 21).

Hanson and Gottesman (2012) caution against adopting a stigmatised and erroneous view that people with schizophrenia are vulnerable and not resilient and use the high remission rates to argue that resilience is responsible for this; however, they also acknowledge that how this occurs is a major puzzle for resilience research. Perhaps, as is the case with the co-existence of both a state of mental health and a state of mental illness in the same individual, it may be possible that states of resilience and vulnerability also co-exist.

Theories of resilience suggest that people and their support systems may be vulnerable to some stressors and not others and may demonstrate resilience in some situations and not others (Leipold & Greve 2009; Luthar 2006; Masten & Obradovic 2006; Rutter 2006b). Therefore, the issues causing decompensation are highly individual, not only for the person but also within the experience of schizophrenia (Leipold & Greve 2009; Luthar 2006; Masten & Obradovic 2006; Rutter 2006b). People who experience schizophrenia can and have developed competence and coping in the face of their own particular adversities and illness experiences and therefore these need to be understood (Hanson & Gottesman 2012). Development of competence and coping, also known as resilience, brings the ability to anticipate, perceive and respond (Hanson & Gottesman 2012).

Despite Garmezy (1987) and Rodnick et al's (1984) early observations of competence in people who have schizophrenia, little to no research on resilience and people who live with schizophrenia has occurred since the work of Bleuler (1978) in the 1940s and Garmezy (Garmezy 1971) in the 1970s. Existing resilience knowledge has been built upon studies of invulnerability, or those who have resisted stress and not those who have succumbed to stress and developed a mental illness, such as schizophrenia.

Some published studies have identified the presence of resilience in small cohorts of people who experience schizophrenia but did not explain or shed any light on the meaning of resilience for research participants within that experience (Andresen, Caputi & Oades 2006; Andresen, Oades & Caputi 2003; Geanellos 2005; Harrow et al. 2005) and therefore questions arise as to the meaning of the resilience that was identified.

The current lack of research creates a significant gap in literature and supports the need for research to begin to understand what resilience means for people who experience schizophrenia. Research on building resilience is one thing but understanding what resilience means for people who have schizophrenia is another. This research goes some way to filling this void. This research which explores the meaning of resilience for people who experience schizophrenia is new and therefore significant and represents a contribution to the gap in knowledge.

The next chapter will present and discuss details of the research design including the methodology and all aspects of the methods used to conduct the study to explore the meaning of resilience for people who experience schizophrenia.

CHAPTER THREE

RESEARCH DESIGN

Introduction

This chapter includes extensive discussion on the role of the researcher within the research, the choice of research paradigm, the underlying research question, the methodology and methods used and why they were considered appropriate. Within the discussion of methods, exemplars have been provided to demonstrate how van Kaam's Psychophenomenological model (Eppard & Anderson 1998) was used to analyse the participants' data. The chapter concludes with a discussion on how Lincoln and Guba's (1985) criteria for rigour in data analysis has been addressed within this thesis.

Research aim

The aim of this research was to understand the lived experience of people diagnosed with schizophrenia and to interpret the meaning of resilience as described by people who experience schizophrenia.

The role of the researcher

The researcher, as an important component of the research process, holds particular ontological positions about the nature of being human and the nature of the reality in which humans live, 'what is real' or 'what is known' (Dombro 2007, p. 106), or a basic theory about existence (Kinash 2010b). In addition to 'knowing', researchers have epistemological views or 'ways of knowing', that is, how the known becomes known, or 'how it is that I come to know' (Dombro 2007, p. 106; Kinash 2010b). Furthermore, a particular methodological 'posture' is taken on how something should be studied, or the particular inquiry process to be adopted (Dombro 2007, p. 100; Guba & Lincoln

2005). A researcher's ontological, epistemological and methodological positions make up the philosophical paradigm that, in turn, shapes how the researcher sees and acts within the world. Ontology, epistemology and methodology are therefore a 'basic set of beliefs that guides action' (Guba 1990, cited in Denzin & Lincoln 2008, p. 22).

It is necessary, therefore, for researchers to critically reflect on themself as the person conducting the research (Guba & Lincoln 2005). Guba and Lincoln call this action 'reflexivity' and deem it necessary when considering the choice of research problem, the research process and how findings are represented (Guba & Lincoln 2005, p. 210). The act of engaging in reflexivity, undertaken from the beginning, reveals the researchers ontology, and epistemology and determines an appropriate research method, methodology and methods with which to inform and guide the research process (Dombro 2007; Guba & Lincoln 2005).

Ontology and epistemology

The aim of this research was to understand the meaning of resilience for people who experience schizophrenia. The inquiry was not the search for the truth of a 'thing' as a discrete, measurable object, which would require a *rationalist* ontology (Kinash 2010b), but rather to understand a phenomenon which according to Kinash (2010b) may have multiple realities, and no right or wrong answers. This approach is a *naturalistic* ontology and is the view taken within this research.

Epistemology is about the co-creation of a shared understanding between the knower (participant) and the respondent (researcher) which effectively contributes to the researcher being able to correctly interpret and represent the information (Denzin & Lincoln 2003). I have no lived experience of schizophrenia and had not, prior to

commencing undergraduate nursing education, known or been involved with anyone who experienced schizophrenia. Thus, my epistemological reality has been created from professional nursing and academic concepts.

The knowledge that accompanies me into the research process was gained through both undergraduate and post-graduate nursing curricula, and in particular, the mental health content. The way in which I have built understanding around this knowledge is through practice as a mental health nurse in a variety of settings, including triage for people in crisis, acute hospital-based care and engaging with people living in the community. Through mental health nursing practice, I have been exposed to the lived experience of people with mental illness, although my particular lens is from a professional stance.

Initially my practice was within a highly structured in-patient ward environment working within the medical model of treatment for mental illness. The crisis and community roles exposed me further to the lived experience of people and underpinned a need for me to come to understand other ways of working, in particular approaches and nursing practice that was more person centred, strengths based and inclusive of families. My views, therefore, are broadly composed of people who experience mental illness, and their families within their communities.

The way in which I have continued to develop my ways of knowing, my epistemology, is through on-going practice in the community and also through teaching mental health curricula to others, including pre-registration nursing students, post graduate practicing mental health nurses and members of the New South Wales Police Force. An ongoing pursuit of knowledge to support teaching endeavours has resulted in continuous synthesis of new knowledge into my own mental health nursing practice which has in

turn been informed and moulded by observing the real-life experiences of those with whom I work, including working with people who have been diagnosed with schizophrenia. I have therefore evolved, and continue to be, through being shaped by people's experiences (Kinash 2010a) and my interpretation of the research findings is informed by this epistemology.

As stated I have developed my own beliefs about schizophrenia, which are informed by my education and experience. These beliefs have contributed to the formation of ideas for how I wanted to study schizophrenia. My underlying beliefs are that schizophrenia is an illness, and that the majority of people who are diagnosed with it achieve a good outcome. I believe there could also be positive aspects to the journey with schizophrenia for some people who are living with it, and I adopt a positive attitude towards working with people who are experiencing it. I particularly value the subjective experiences of individuals because the strengths of the person to achieve a good outcome and to derive positive benefits from the journey are to be found within the individual. The truth or reality of an experience is to be derived through listening to the voices of those who have had the experience (Guba & Lincoln 2005). I hold strongly to the principle of 'nothing about me without me' (Nelson et al. 1998, p. 881), which informed my approach for the research design. Therefore, my philosophy for this particular study which explores the meaning of resilience as described by people who experience schizophrenia means that people who have had the experience must be the principal players.

Quantitative research methods on this occasion, do not facilitate such an exploration of lived experiences and therefore a qualitative research methodology was appropriate for this study (Moustakas 1994). Qualitative methodology seeks to explain meanings and

essences of experiences and are also aptly suited to my own epistemology (Moustakas 1994). What is being sought is not the *truth* as to whether a situation actually happened or not, but rather, the meaning of the experience to the person who had it (Polkinghorne 2007).

This research sought to understand the essence of the experience of resilience for a person who is living with a diagnosis of schizophrenia. Peter Chadwick is a psychologist and researcher who has also experienced psychosis and thus refers to himself as both a *peer-professional* and a *user-academic* (Chadwick 2007). Chadwick finds phenomenology to be an appropriate method for 'engaging with the fine details of sufferer's experiences' (Chadwick 2007, p. 166). For this research, a phenomenological approach was used to look deeply within the stories of people with schizophrenia to inquire into resilience, as they saw it. The research therefore, was conducted with the intent to privilege the voice of people who are living with this mental health issue. What was examined was the meaning of resilience for people who experience schizophrenia and *not* the qualities and characteristics of a resilient person who also has schizophrenia.

Moustakas (1994) speaks of the types of questions that might underlie phenomenological inquiry, such as, what is the meaning of the phenomenon (resilience)? What are the relations between resilience and schizophrenia for the person? What does a person who experiences schizophrenia believe resilience to be? How does the person experience it and what is their relationship to it? These were questions that arose for me and which were the catalyst for this research.

Phenomenological research combines the raw experience, as reflected upon by the person who has had it, with the listening researcher, who in turn strives to grasp concealed meanings and arrive at complete descriptions of the experience (Moustakas 1994). The researcher must reflect deeply, again and again, to create an intuitive grasp of the essence of the experience and then this must be unified with the participant's external perceptions (Moustakas 1994). The role of the researcher is, therefore, intuitively embedded within phenomenological research findings and needs to be made explicit.

The term *imaginative variation* explains the process of taking an intuitive grasp to propose a structural description of the phenomenon;

> *The task of imaginative variation is to seek possible meanings through the utilisation of imagination, varying the frames of reference, employing polarities and reversals, and approaching the phenomenon from divergent perspectives, different positions, roles, or functions. The aim is to arrive at structural descriptions of an experience . . . the "how" that speaks to conditions that illuminate the "what" of experience. How did the experience of the phenomenon come to be what it is?*

(Moustakas 1994, p. 97)

The perspective I bring to this research and to the process of imaginative variation, is that of my nurse self. As recommended by Bohm (1998, cited in Oiler-Boyd 2001), I used a mixture of my personal self and my nurse-educated self, which is represented by memory, imagery, ideas, and feelings, to order attention to and direct my research design and actions. I also bring my ontological, epistemological and methodological positions with me, as previously discussed, and as such it was important to maintain mindfulness of these considerations as my paradigm interacted with the research process.

Original phenomenological inquiry requires the researcher to 'bracket out' or 'set aside' the self from the research process (Dowling 2007; van Kaam 1969; von Zuben 2011). To do this, researchers need to examine the beliefs and ideas that they hold, and to be aware of how these may influence the research process. It is also important to acknowledge that this may occur sub-consciously and that the researcher needs to maintain a reflective, self-checking stance to know when this might be so (Crotty 1996; van Kaam 1969; van Manen 2007). The researcher, as an intrinsic part of the research process, acknowledges that their own self and the interpretation of results cannot really be separated (Dowling 2007; von Zuben 2011). As such, self-awareness in the form of reflexivity was used to continually question myself about my presumptions and bias. According to van Kaam (1969), bracketing the self out of the inquiry always starts with awareness of self within the inquiry. The overriding purpose of phenomenological inquiry is to interpret the meaning attributed to experiences (Crotty 1996) and not to make the data fit the researcher's beliefs and ideas.

Traditionally, it is not often that people with a mental illness have been given the opportunity to have their knowledge and experience heard and incorporated in research on mental illness, including schizophrenia. Research methods have been based on using the observations of professionals (Amering, Schrank & Wallcraft 2009; Loveland, Randall & Corrigan 2005). In 'The Wounded Storyteller', Frank (1995, preface xii) states that;

> *Stories of people trying to sort out who they are figure prominently on the landscape of postmodern times. Those who have been objects of others' reports are now telling their own stories. As they do so, they define the ethic of our times: an ethic of voice, affording each a right to speak her own truth, in her own words.*

The ethics of the silenced voice resonated with me because the disempowering consequences of not having a voice were very much in evidence throughout the review of literature for this work. As Frank (1995) states, people's stories are part of the post-modern landscape and they are also being actively encouraged within the shifting paradigm towards consumer inclusion in all aspects of mental health services. This extends to inclusion of consumers as leaders and partners within research, and not only as subjects (Banfield et al. 2011; Jorm et al. 2002; Thornicroft et al. 2002; Tomlinson et al. 2009).

The phrase 'nothing about me without me' was adopted as a guiding principle for the inclusion of consumers (Delbanco et al. 2001, p. 144; Nelson et al. 1998, p. 881). The way in which this research has observed this guiding principle is to bring the participant's voices through strongly by using a phenomenological research approach. The word phenomenon means 'to flare up', 'to show itself', 'to appear' (Moustakas 1994) with the aim of this phenomenological inquiry being to understand phenomena through interpreting consumer's reflections upon their natural experiences of schizophrenia and what resilience means for them and to make meaning from their descriptions (Crotty 1996; Moustakas 1994; Norlyk & Harder 2010).

Whilst resilience has been extensively researched in several contexts (childhood development, education, sport) it remains an enigma with regard to how it appears or what it means in the context of schizophrenia. Resilience is a phenomenon that has many different interpretations, depending on the view being taken, and leading researchers (Luthar, Sawyer & Brown 2006; Obradovic, Burt & Masten 2006; Rutter 2006b) have suggested that resilience needs to be studied within the context of inquiry to ascertain the form or essence it takes. Phenomenological research methods are

suitable for the study of nebulous or ill-defined topics (Priest 2004). Linschoten (1987, p. 75) states that the phenomenologist is reflectively orientated 'to the region of lived experience where the phenomenon dwells in recognisable form'. Thus a phenomenological approach is suitable for recognising and valuing the voices of research participants and for exploring nebulous phenomena such as resilience. Therefore, to gain understanding, it was without question that I wanted to speak directly with people who have schizophrenia in order to inquire about the meaning of resilience for them. This will be discussed in data collection, which is explained in greater detail later in the chapter.

Phenomenology is both a philosophy and a research methodology and thus it is ideal for a Doctor of Philosophy. The philosophy of phenomenology was developed by Edmund Husserl (1859-1938) who subsequently developed a method for phenomenological inquiry to render human experience interpretable (Klein & Westcott 1994; Spiegelberg & Schuhmann 1994; van Manen 1997). A diverse range of methods for inquiry have since been developed (Klein & Westcott 1994) and there are important differences between philosophical phenomenology and the methodical or scientific phenomenology used to interpret human experience (Giorgi 1997). Therefore the philosophical and scientific methodological stance taken in an inquiry needs to be understood and explained (Priest 2004).

Philosophical phenomenology aims to describe essential universal structures and has a requirement for the inquiring person to bracket their judgement, called 'bracketing' and to concentrate on intuiting the essential universal structure of the phenomenon under investigation (Dowling 2007; Giorgi 1997; Moustakas 1994; van Manen 1997; van Manen 2007). For example, to believe the equation $3 + 2 = 5$ to be true, it is necessary

to bracket our tendency to believe it is true and instead to rigorously reflect upon the underlying essential structure that is the basis of arriving at its truth (Klein & Westcott 1994). Another example used by Husserl (Klein & Westcott 1994) is that of holding a cube in our hand. We can see only those sides of the cube that present to our vision and in order to know that it is in fact a cube, we need to intentionally reflect upon and intuit the underlying essential structure of a cube to know that what we are holding is a cube. The act of bracketing judgement in order to intentionally apprehend and describe the essence of an object is a component of philosophical phenomenology's descriptive method of inquiry (Klein & Westcott 1994).

Interpretive phenomenology uses different methods for inquiry. The necessary reason for this according to Giorgi (1997) is that philosophical phenomenology is based on the reflections of one's own experiences whereas interpretive phenomenology uses the reflective descriptions of others about their own experiences. The inquirer or researcher does not have first person contact with the essential structure or first person experience of the phenomena being described. In the context of the example provided previously, they are not holding the cube (Dowling 2007; Giorgi 1997; Moustakas 1994; van Manen 1997; van Manen 2007) and therefore cannot intentionally access the essential experience or structure. Others 'lived experience' of the phenomenon are instead used to interpret the features and essential structures and the subjective reality of these is accepted (van Manen 1990; 1997; 2007).

Lived experience, as understood within the philosophy of Husserl, is the experience currently being lived, in real time, in the pre-conscious state before the consciousness grabs hold of it to make meaning of the experience (Crotty 1996). Research methods based on Husserl's view require watching something as it occurs and inquiring directly

into that which is seen, and not after conscious understanding had been applied to explain it (Crotty 1996). This presents a dilemma for a researcher attempting to interpret others' descriptions of phenomena as it is a reflective stance that is being taken. Nonetheless, the person who has lived the experience is able to describe the experience. Intentionally inquiring on something as it is occurring according to Husserl's philosophy, leads to a *description* of the phenomenon. Not having access directly to the phenomena requires *interpreting* it from the experiences of others. The difference between description and interpretation requires introduction of another phenomenological philosophy and method of inquiry created by Martin Heidegger.

Heidegger (1889-1976) was a colleague and student of Husserl (von Zuben 2011). He held different ideas for how lived experience is explored (Dowling 2007) based on the view that consciousness cannot be separated from human existence and that interpretation occurs simultaneously with the experience, rather than through later reflection. Therefore it cannot really be captured in a pre-reflective state as asserted by Husserl (Dowling 2007; Polkinghorne 1983). Each is understood in the context of the other through *interpretation* (Polkinghorne 1983). Although the researcher hasn't had the experience and does not have direct access to the phenomena they can interpret the essential structures through the reflections of others who have lived the experience (Giorgi 1985). In experiencing the phenomena, the person has reacted and has reflectively made meaning of this reaction (van Manen 1997).

Van Manen (2007), argued that aspects of lived experience can only be appropriated through reflection, as though the past were present again (Edwards 2001; Sokolowski 2000). Gadamer, another proponent of Heidegger introduced the concept of universality in which the person who describes the experience and the person who

understands are 'connected by common human consciousness which makes understanding possible' (Dowling 2007, p. 134).

The method of phenomenological reduction is used to come to know the phenomena as they show themselves through descriptions of lived experience (Holloway & Wheeler 2002; Parse 1993). The researcher becomes intimate and connects with the descriptions provided and intuits deeper into the essence (Smith & Osborn 2009) to analyse and describe particulars and to then distil general essences and relations among essences to arrive at an interpretation of the meaning of the phenomena (Spiegelberg & Schuhmann 1994). This is called the phenomenological reduction in which the researcher interprets the description (participant's voice) to capture the essential features and structure of the experience (Oiler-Boyd 2001). These features may be found in a phrase or a sentence that appears across data in common occurrences and expresses the essence (Churchill 2002). Findings are made from the participant's quotations, the researcher's descriptions of the phenomena and the researcher's interpretation of the structural essences of situations in which participants have attached their meaning (Norlyk & Harder 2010).

Through the act of interpretation, the researcher's pre-conceptions are also integrated into the research findings because they are linguistically embedded within the language that we use to make meaning and therefore cannot be separated (Dowling 2007; Norlyk & Harder 2010). The researcher is an embedded part of the research findings. Therefore, the researcher is required to recognise and be as open as possible about the influences of self that they bring to the process of interpreting the experiences of others (Giorgi 1997). In Husserl's philosophy, the researcher suspends judgement by bracketing themselves from the research process but in Heidegger's the researcher is an acknowledged part of the research process. When following Heideggarian methodology,

as this research does, it is essential to include a discussion on the researcher's influences and this has been done in the discussion on the role of the researcher within this thesis.

As the method of research in this study is asking participants to describe their own experiences of schizophrenia and their meaning for resilience, which the researcher will then be interpreting, the phenomenological stance of 'best fit' is that of Heidegger. Thus the research design uses scientific phenomenology and is based on Heideggarian methods for researching lived experiences.

Phenomenological Research Methods

There are many variations of phenomenological research methods. Van Kaam's psycho-phenomenological method (PPM) (Eppard & Anderson 1998), is used for exploring lived experiences, and for this reason, PPM has also been used in many nursing studies (Crotty 1996; Mackey 2005; Norlyk & Harder 2010; Pereira 2012; Salmon 2012). The method is particularly suitable for exploring experiences such as chronic illness, pain and nursing care (Butcher, Holkup & Buckwalter 2001; Eppard & Anderson 1995; Mason, Rice & Records 2005; Norlyk & Harder 2010). It has been used for small to large sample sizes in studies ranging from one person to four hundred people and also for analysing large amounts of narrative data (Eppard & Anderson 1998). PPM has also been used as the method for data analysis in dissertations by nurses for exploring aspects of lived experience (Ballmer 1999; Brandt 2005; Habegger 1997; Palyo 1995) and is the method that was chosen for data analysis within this thesis.

PPM is a four step, twelve stage method (Eppard & Anderson 1998) and the finer details of PPM and how they have been utilised for the research described in this thesis will be discussed later in this chapter.

Ethical considerations

Ethical approval to conduct the research was obtained from the Human Research Ethics Committee at the University of Wollongong; New South Wales, Australia (refer Appendix 1). Ethical approval was also obtained from the health service organisation for the area in which the research was conducted; the Greater Southern Area Health Service, New South Wales, Australia (now known as the Southern New South Wales Local Health District) (refer Appendix 2).

One of the major concerns of the ethics committees for both organisations was the potential vulnerability of the intended research participants, and therefore the literature exploring the reality of research participation and vulnerability was of interest. Vulnerable populations are social groups of people who are more susceptible to having higher morbidity, higher mortality and lower life expectancy and who are without resources, power or status (Flaskerud & Winslow 2010). Within a research context, there is a considerable disparity between the power of the researcher and the organisation behind the researcher and a vulnerable research participant and it is important that researchers maintain sensitivity to this vulnerability (Anderson & Hatton 2000).

Very little research has been conducted to explore vulnerable people's experiences of participating in research. Taylor et al (2010b) interviewed 79 vulnerable people after research participation exploring the issue of suicide and they identified five key themes participants related to their experiences of being part of research; first; they valued the altruism of participation, second; they valued being involved, third; they perceived therapeutic effect and four; found it to be an enjoyable experience. The first four themes were positive in nature. The fifth theme (received between 2.5 per cent and

15.2 per cent of responses) was related to feelings of distress and depression experienced while answering particular questions. These were most often questions asking them to talk about illness experiences. Despite this, those who indicated some distress also stated that the whole process was 'overall OK' and 'interesting' (Taylor et al. 2010b, p. 345).

The perception of vulnerability is a complex issue with very few measures available with which to make a determination of vulnerability pre-research. One concern is the potential for participants to experience distress (Taylor et al. 2010b). The information accompanying the invitation to participate in this study (refer Appendix 3) contained the following ethical considerations;

> *We can foresee no risks for you, however, should content of a personally distressing nature arise during the interview, provision has been made for a debriefing session to be available on request, through community mental health, to assist in reducing symptoms of distress with follow-up counselling if required. Your involvement in the study is voluntary and you may withdraw your participation from the study at any time and withdraw any data that you have provided up to commencement of the process where multiple transcript interview data is analysed together. Refusal to participate in the study will not affect your relationship with the University of Wollongong, the Greater Southern Area Health Service or the Community Mental Health Team in your area.*

Furthermore, The American Psychiatric Association (APA) produced a set of recommendations aimed at promoting research involving people who experience psychiatric conditions and also to ensure ethical conduct of that research (American Psychiatric Association 2006). The recommendations that relate directly to ethical conduct have been provided in Table 8, along with a description of the way in which they have been addressed within this research. The recommendations related to promoting research have been deleted for brevity.

Table 8: APA recommendations for ethical research

	RECOMMENDATION	IN THIS STUDY ….
1	Research must be collaborative between agencies and organisations that ensure ethical rigour.	Ethical approval was received from the University of Wollongong and the Greater Southern Area Health Service and both were also scrutinised by ASRB/SRR prior to recruiting participants.
3	People diagnosed with mental illness may have impaired decisional capacity. Risk is determined according to criteria for research with children (minimal/ minor increase over minimal/more than minor increase over minimal.	The risk associated with this research was judged to be minimal, however the criteria of the Human Ethics Research Committee of the University of Wollongong related to informed consent was met.
4	Research which may prolong or exacerbate symptoms can be justified when clear plans to minimise effects are in place.	This research was not of a clinical nature and did not involve working directly with symptoms. A strategy was in place to manage potential for negative effects related to distress and to ensure the safety of participants.
5	Investigators are to consider *decisional capacity* and explicitly discuss it within ethics applications.	Literature on the concept of decisional capacity was reviewed (Carpenter et al. 2000; Kaup et al. 2011; Kim 2006; Palmer 2007; Prentice et al. 2003). The principles relevant to this study were informed consent (Gupta & Kharawala 2012), voluntarism (Geppert & Abbott 2007; Roberts 2002) and continued consent (Mueller & Instone 2008). The criterion associated with these was met within this research as indicated by being granted approval by institutional committees.
6	The use of proxy decision makers where decisional capacity has been judged to be impaired.	Decisional capacity was judged to be present through consideration of the principles reviewed for Point 5.
9	Research design must be ethically sound with effective safeguards to protect the wellbeing and rights of participants with mental illness.	Criteria met as indicated by approval being granted by institutional ethics boards.
10	Conflict of interest should be avoided and must be disclosed when present.	There were no conflicts of interest within the areas recommended for consideration; study funding (student research), recruitment, consent, data collection, analysis or interpretation.
11	Investigators are to remain aware of ethical and regulatory requirements for human studies.	Tertiary level course work on ethical considerations was completed by the researcher. Regulatory requirement compliance was ensured within the supervision process of this research.

Research participants

The choice of a particular type of participant who was likely to have experienced the phenomenon under investigation is necessary for phenomenological research (Crotty 1996). It was necessary to conduct the research with a purposive sample of people who have had the experience, and can therefore speak about schizophrenia and the meaning that resilience has for them (Norlyk & Harder 2010; Polgar & Thomas 2008). Therefore, it was necessary for participants to have experienced schizophrenia.

Crotty (1996, p. 172) suggests that participants in phenomenological research need to be able to 'reflect, focus, intuit and describe'. During interviews, my professional mental health nurse experience was used to ascertain whether participants had the reality-based capacity to reflect, focus, intuit and describe. I was mindful of the logical and rational progression of the participant's dialogue and whether there were any active psychotic symptoms that may have been interfering with participant's reflections, sense making and conversational ability. A similar approach was adopted by Moller and Zausziewski (2011) in their phenomenological study of the psychotic adjustment process with people who also may have had impaired reality capacity.

Recruitment of participants

People who have experienced schizophrenia were members of the population from which the sample was drawn, therefore the sample was purposive (Palmier-Claus et al. 2011; Polgar & Thomas 2008). Not all members of this population had an equal chance of selection, making it a non-random sample (Palmier-Claus et al. 2011; Polgar & Thomas 2008).

Sample size was not pre-determined. Giorgi (2008) states that at least three participants are necessary to be able to phenomenologically interpret essences. Mason (2010) argues that one occurrence of a piece of information is sufficient to bring it to the awareness of the researcher and that collecting more data does not necessarily lead to having more information. A review by Norlyk and Harder (2010) of thirty seven phenomenological nursing studies revealed that numbers of participants ranged from one to seventy six with no easily determinable rationale as to why (Norlyk & Harder 2010). Phenomenological research is concerned with collecting reflective descriptions, interpreting essences and making meaning, rather than needing specific numbers of participants to be able to make generalisable statements (Mason 2010; Pereira 2012; van Manen 1997), therefore, one participant can be sufficient to describe phenomena.

Participants were initially sourced from within an inland rural city and a coastal rural town in New South Wales, Australia. These particular geographical locations were chosen because I wanted to interview people in person, at a place of their choosing and given the financial and time limitations of a PhD these areas were accessible. The result was that I drove between one and five hours to conduct each interview and I covered around 2,500 kilometres to conduct all fourteen interviews.

I attended team meetings of Community Mental Health Case Managers within these geographical areas were attended to brief staff on the research purpose and procedures and to discuss the best ways to raise awareness of the study with potential participants within their areas. Two mental health teams were each provided with 30 stamped envelopes containing research information packs and were asked to mail them to people known to them who fitted the inclusion criteria (diagnosed with schizophrenia and living in the community).   Research packs contained research information (refer

Appendix 4), the participant consent form (refer Appendix 5) and a stamped return envelope personally addressed to the researcher at the University of Wollongong. Consenting participants were asked to return a signed consent form in the stamped envelope provided directly to the researcher.   The identity of participants only became known to the researcher upon receiving a consent form, a telephone call or an email message from participants to indicate their desire to participate.   Members of the mental health service who mailed out invitations do not know who chose to participate in the research.

I was not aware of how many of the 60 research packs were actually mailed out. I had not received any enquiries from potential participants and therefore several phone calls and two further visits were made to each community mental health team to remind and prompt for the research packs to be mailed out. Following this, only four signed consent forms were received in the mail.

After interviews commenced, one participant offered to make information on this research project available through a self-help group for people with schizophrenia. An amendment to ethics approval was gained to allow for this recruitment method. Six research packs were provided and a further three people consented.   Another ethics amendment was gained through the University Human Research Ethics Committee to source participants through the Australian Schizophrenia Research Bank (ASRB), (previously known, at the commencement of this research, as the Schizophrenia Research Register (SRR)). This is an organisation that seeks volunteer enrolment from people with schizophrenia to participate in research related to schizophrenia (SRR 2008).

Individuals sourced through the ASRB were recruited by the Schizophrenia Research Register from treatment settings, community services, over the internet and through multi-media recruitment campaigns (SRR 2008). For this study, a further eight people were sourced who expressed interest through the ASRB to be interviewed. Six out of the eight were interviewed. The two males that were not interviewed informed me they were experiencing symptoms at the time of contact to arrange an interview and both felt that they did not want to participate at that particular time. One further ethics approval was gained to conduct recorded telephone interviews and this resulted in one more interview. Fourteen participants were interviewed over a period of 18 months. Ten males and four females were interviewed with an age range of 29 – 60 years and an average age of 49.7 years. The gender split is indicative of the incidence of schizophrenia, which is 1:4 and is higher in males than females (McGrath 2006). The 'challenges of recruitment' is a lesson learned in the process of this research apprenticeship.

The use of personal interviews for collecting data is time and labour intensive. However, data collection needs to continue until the researcher develops a sense that no new information is emerging (Crotty 1996; Munhall 2006). This is consistent with sampling within a phenomenological method (Crotty 1996). The process of data collection took eighteen months due to the difficulties experienced in obtaining participants. Interview transcripts were prepared after each interview and therefore, some familiarity with the data developed during the collection period. During the ninth and tenth interviews I recall gaining a sense of an underlying pattern to what I was hearing. This was discussed with the research supervisors and we decided to continue with the last few interviews that had already been arranged. There was a definite sense

that there was nothing new emerging at the fourteenth and final booked interview and the decision was taken to stop recruiting.

Inclusion criteria

Selection criteria included people over 18 years of age who self-identified or were identified by mental health clinicians as living with schizophrenia. They were living independently in the community, were not acutely psychotic, may have had chronic residual symptoms, were not currently residing in any mental health facility, were not subject to any compulsory treatment orders and they spoke conversational English.

Interviews

Using personal interview as the means of data collection is embedded within methodologies that allow the interview data to be interpreted for meaning. Qualitative research methodologies are used to create meaning through interpreting human experience in a particular context (Loveland, Randall & Corrigan 2005). They are also used to provide a framework for understanding how a process occurs (Polgar & Thomas 2008). Phenomenological methods support the use of interviews as a means for obtaining descriptions of experience within first person accounts (Moustakas 1994). An interview method that would cause participants to reflect on their experience and to discuss the meaning was considered the most appropriate.

Initially a list of questions had been prepared, primarily as a prop for an anxious novice researcher. However on reflection, the structure became more open and it was decided by the researcher to commence the interviews with only one question; "What does resilience mean for you"? Participant's dialogue flowed early in the interview and they talked at length about their journey without much further prompting.

Strategies employed to gather as much information as possible included using silences as pauses between reflections and giving participants time to gather their next thought or 'self-interpretation' (Rennie 1989, p. 7), to revisit the last sentence as a prompt when it became apparent that the silence was a conclusion to dialogue, and to choose to remain silent unless the participant asked or non-verbally indicated they wanted some interaction. I did not vocalise any leading or directive statements or questions. When participants indicated that they had finished and I then concluded the interview and thanked them for their time. Interviews ranged in length from the shortest at 30 minutes through to the longest at 60 minutes. The average length of interview was 40 minutes.

Demographics

Table 9: Participant demographics

PARTICIPANT DEMOGRAPHICS		
AGE RANGE	MALE	FEMALE
26-30	1	0
31-35	0	0
36-40	1	0
41-45	2	0
46-50	3	2
51-55	2	0
56-60	0	2
61-65	0	0
66-70	1	0
Total	10	4

Data collection

In-person interviews were conducted with 13 of the 14 participants and one was via telephone. All interviews were conducted by the researcher. Nine of the 14 interviews were conducted in the participant's home at their invitation, two were conducted in a coffee shop, one was conducted at the participant's workplace, one at a Community Health Centre, one in a university room, and one was conducted via telephone.

Interviews were all conducted in a location chosen by the participant and there was no financial or other reward for participation. All interviews were tape-recorded to enable verbatim transcriptions to be produced. Verbatim transcripts were transcribed by the researcher. Data were de-identified. Participants were informed they could discontinue participation up until de-identification and merging of data. None withdrew participation.

Each transcript was copied separately into NVivo 9™ data management program (Bazeley 2007), however, NVivo 9™ was used for data storage and management only. Analysis was conducted manually by the researcher. Braun and Clarke (2006) suggest that it is necessary to become actively familiar with the depth and breadth of the data through immersion in the data prior to conducting the analysis. This process was facilitated through the researcher conducting all data collection, transcription and analysis.

Data analysis using van Kaam's Psychophenomenological Method (PPM)

As previously indicated data familiarity occurred during the transcription phase, however, data analysis commenced in earnest after all fourteen interviews had been carried out and transcribed in full. The analysis of data conformed to van Kaam's PPM (Crotty 1996; Eppard & Anderson 1998). The assumption of PPM is that while experiences may be different for each individual, there will be essential structures of the experience that are the same for individuals sharing an experience (Eppard & Anderson 1998). The aim of PPM is to identify the essential structural elements of the experience, also referred to as themes. The themes 'must be explicitly expressed by some of the sample, be implicitly or explicitly expressed by the majority and be compatible with the whole' (Eppard & Anderson 1998, p. 400).

PPM has been used to analyse data from both large and small studies of people's lived experience (Futrell, Wondolowski & Mitchell 1993; Mason, Rice & Records 2005; Moller & Zauszniewski 2011; Parse 1993; Sandelowski & Pollock 1986) and is an appropriate analytical approach for this research. Giorgi (2008) argues that at least three participants are necessary to be able to interpret essential structures and to capture the essence of the phenomenon. This study has 14 participants.

Van Kaam's original PPM model was modified by Anderson and Eppard (1998) to a four stage, twelve step method (shown in Table 10) which was examined and declared by van Kaam to be faithful to his work (Eppard & Anderson 1998).

Table 10: van Kaam's Psychophenomenological Method

THE PSYCHOPHENOMENOLOGICAL METHOD (PPM)

Stage One – Analysis

1. Obtain first general description
2. Differentiate structural elements (preliminary groupings)
3. Eliminate repetitious statements and redundancies
4. Tentative relation of structural elements (elimination)
5. List statements (explication)
6. Process of methodological reflection
7. Determine potential elements of integral structure
8. Engage in psychophenomenological situational reflection

Stage Two – Translation

9. Translate into the metalanguage of science (hypothetical identification)

Stage Three - Transposition

10. Determine fidelity (application)

Stage Four – Phenomenological Reflection

11. Produce a paradigm of the experience (final identification)
12. Statement of limits

(Eppard & Anderson 1998)

The next pages in this chapter contain a discussion of how van Kaam's PPM method has been utilised to analyse the data and to answer the research question. Within each of the four stages, twelve steps and their sub-steps, examples have been given to provide further clarity of the analysis process that was undertaken. The examples provided do not represent the final findings, but rather the progress of data through the various stages, steps and shifting perspectives of analysis.

STAGE ONE - ANALYSIS

Step one: obtain first general description

General descriptions of the phenomenon under inquiry were obtained through interviewing people who were living with schizophrenia and their dialogue was captured on a recording device and verbatim transcripts were produced.

1a   Carefully read each situational description in its entirety

The situation is schizophrenia and the description is the participant's transcript; their interview dialogue answering the research question on the meaning of resilience. Therefore, when using the term description, a transcript is being referred to.

I conducted and recorded all participant interviews and then embedded myself within them in the process of transcribing and typing the interviews. Through this repeated contact I became familiar with individual descriptions.

1b *Obtain first general impression of experience's structure*

Early impressions began to form that there were similarities in the order in which participants constructed their stories. Telling their story from the development of their illness to the present time was common for participants and this gave an impression of there being structural elements to the experience of the schizophrenia. This needed careful consideration. The impressions gained were noted for future analysis. An example is shown in Table 11.

Table 11: Early impressions from reading transcripts

EXCERPT FROM RESEARCH NOTEBOOK
Overall impression? Constantly challenging experience.
The sense of empowerment/hope? I felt participants conveyed while telling their stories returned after reading some transcripts.
Seems to be a similar construct to the stories. Is there an order or sequence to what is being described? Are they responding like in a typical psych interview? What does that mean? (Discuss with Supervisors?)
Family and meds are a frequent feature within descriptions
Some mentioning a point of change, a turning point at which things are different? Who was this the case for? Is it structurally meaningful?
Uncomfortable while transcribing dialogue about the health system? Negatively viewed! What meaning does it have? What's my involvement as a professional (specific need to bracket?).

Step two: differentiate structural elements (preliminary groupings)

2a *Re-read each description*

Descriptions (transcripts) were read several times. Notes were made of impressions developed during reading which included some of those shown in Table 11.

2b   *Record each possible structural element*

As each interview was transcribed, an impression was built for the first structural element which was the meaning of resilience that was provided within obvious participant statements, such as *'resilience is ...'*, or, *'resilience means to me ....'*. An example of individual participant definitions which contributed to forming the meaning of resilience is shown in Table 12.

Table 12: Participant descriptions of the meaning of resilience

PARTICIPANT NUMBER AND QUOTE FROM DESCRIPTION	
1	Dignity of risk comes into resilience. When someone wants to make an adventure into the outside world someone will say "it's a risk we don't want you to do that". But having a go. To keep having a go and to get that education across to them. It's not going to happen the first time you have to try and try and try. Find work, a hobby or exercise you have to try and try and try. This is about resilience, to being able to try again that you have failed. To see it as failure is wrong. You need to have another go and stigma goes against that when you fail that everybody is judging you because of your mental illness.
9	So I would see resilience as also not a tool but a characteristic of the human condition that enables you to overcome.
11	Resilience was I went back 6 years ago when it was like I had lost my whole cognitive ability to work and understand and through so it's not giving in to mental health and how they suggested I should have gone on disabilities pension, I tried something else. That's what I call being resilient.
12	Resilience means not going under, just looking on the bright side of things, coping.

In addition to obvious statements for the meaning of resilience, a structural element is also something that may be meaningful for the experience being

researched. Within each description, words and phrases left impressions that they may be meaningful. Within this step of identifying structural elements, the interview data were re-interpreted several times using different intentions towards identifying meaning. Crotty (1996, p. 158) suggests that the researcher asks him or herself if the description is from participant's genuine experience or past experiences, or from the researcher's knowledge or theoretical associations. Furthermore, the element should be abandoned if it is not directly related to participant experience. During this activity, I asked myself, would another person, who knows nothing about this topic, also see the link between the element name and the meaning in the description? This examination is consistent with the phenomenological principal of intentionality (Sokolowski 2000). Meaningful text was highlighted and copied into a list of possible structural elements. See Table 13 for an example of this.

Table 13: Identifying possible structural elements

MEANINGFUL DESCRIPTION	POSSIBLE ELEMENTS
My brother spent three months talking to me about being a victim. He banged his fists he didn't just talk; he made his point really solidly.	Family support Family challenge Being a victim Pressure from others to change

A snapshot example from a list of possible structural elements that emerged in the first analysis is shown in Table 14. If more than one participant mentioned an element, this was recorded and can be seen in the numbering that has been generated beside the listed elements. The heading *Sources* refers to the number

of participants mentioning it and *References* refers to the number of times in total that it was mentioned across interviews.

Table 14: List of possible structural elements from first analysis

POSSIBLE ELEMENTS	SOURCES (N=14)	REFERENCES
Medication	8	30
Hobby	8	16
Supportive people	6	14
Work	7	13
Stress	5	7
Nutrition	4	7
Acceptance	4	6

2c   Retain concrete language of informant

In many cases, but not all, the participant's language was used to name the structural element. There were occasions where other words were used that were more representative of the meaning provided across multiple participants who were saying the same thing.

Step three: eliminate repetitious statements (reduction)

3a   Eliminate repetitious statements and redundancies

At the conclusion of the process of identifying possible structural elements, (Step 2b and Table 13) the original descriptions were re-examined to consider whether the element names were still consistent with the meaning of the surrounding dialogue from which they were drawn. If a meaningful connection was not

implicit, the element was re-evaluated. Some elements were renamed, some were merged and some were deemed redundant and were removed. An example of this is shown in Table 15.

Table 15: Eliminate redundant elements

POSSIBLE ELEMENTS	FINAL ELEMENT
Mental health system closing service Can't cope with change Diagnostic instability	The mental health system

3b   *Note numerical incidences of the same kinds of statements*

Possible structural elements were counted according to the number of participants who described them (see Table 14) and also according to the number of times they were described across interviews. This was just one part of analysis as the researcher is conscious that numerical quantification within qualitative research is not necessary nor is it directive. Within phenomenology, this type of counting was used by van Kaam to provide some rigour for scientists seeking more exact measurement (Eppard & Anderson 1998). Another view is that it relates specific elements to portions of participants and provides support to the element being meaningful and possibly structural (Norlyk & Harder 2010).

Ultimately, in phenomenological research, a single statement can provide an insight as powerful as ten people agreeing on something (Churchill 2002). An example of the way in which counting was made meaningful within this research is that all participants mentioned medication in some way. Therefore, it was

regarded to be an important part of the experience of schizophrenia, and furthermore it was also possibly structural.

Step four: tentative relation of structural elements (elimination)

4a   Relate elements to each other according to compatibility

The preliminary structural elements, such as provided in 2b and in Table 14, were compared with each other to see if there was any pattern or structure evident or whether some were saying the same things or whether there were any standout strong issues. The numerical incidences, which were shown in Table 14, also helped to guide this process. Several possible elements were related together under a new representative structural element and are shown in Table 16.

Table 16: Relating structural elements

STRUCTURAL ELEMENT	SOURCES (N=14)	REFERENCES
1. Use medication	11	35
2. Maintain a supportive family	11	34
3. Work in paid employment	10	22
4. Manage stress	10	22
5. Engage in meaningful pursuits	9	21
6. Use professional help	9	21
7. Engage with other supportive people and groups	8	20
8. Medication side effects	7	13
9. Physical health challenges	5	10
10. Family challenges	5	8

Step five: list statements (explication)

5a   List compatible and incompatible statements in informants' words

Within Table 16, there are two elements related to medication; with the statements underlying each element indicating both the need to use medication and also the challenges caused by medication side effects. Comparing the various compatible and incompatible statements that were made that indicated both good and bad things about medications lead to synthesis of a new statement, using participants words, which acknowledged both the compatibility and incompatibility of their statements; *using medication is an essential choice and it comes with major challenges; seek to understand them.* Dealing with the underlying meaning of compatible and incompatible statements was an important part of interpreting the meaning of resilience and this will be discussed in more depth in Chapter Five, the discussion of findings, however, the incompatibility of statements led to the interpretation of there being both support and challenge within single elements.

5b   Present categories to independent judges for validation

The process and outputs of data analysis were reviewed several times with the research supervisors with clarifications, revisions and improvements made as required.

Step six: process of methodological reflection

6a   Determine potentially valid conforming elements

After the process of reviewing, relating and eliminating redundant elements as shown in Table 16, the meaning of the remaining elements were reflected upon at length, particularly the incompatible statements and emerging structure of both

support and challenge within single elements. Within the remaining elements, two separate tables of elements were created to prepare a structure that acknowledges the interpretation of both support and challenge, as previously described using medication as the example. These are shown in Table 17: The supportive structural element and Table 18: The challenging structural element.

Table 17: The supportive structural element

SUPPORTIVE ELEMENT	SOURCES (N=14)	REFERENCES
1. Use medication	11	35
2. Maintain a supportive family	11	34
3. Work in paid employment	10	22
4. Engage in meaningful pursuits	9	21
5. Use professional help	9	21
6. Engage with other supportive people and groups	8	20
7. Live a healthy lifestyle	6	16

Table 18: The challenging structural element

CHALLENGING ELEMENT	SOURCES (N=14)	REFERENCES
1. Medication side effects	7	13
2. Stress	6	13
3. Physical health challenges	5	10
4. Work stress	5	9
5. Family challenges	5	8
6. Difficult relationships	5	8
7. Health system barriers	4	9
8. Stigma	3	5

Step seven: determine potential elements of integral structure

7a   Relate conforming elements meaningfully to each other based on criteria of essentiality and compatibility

Whilst some elements were supportive in nature and some were challenging, the important structural element to be interpreted from this was the relationships between support and challenge.   This required further reflection and interpretation, and as a result of this, the elements were merged back into single categories (see Table 19), some of which were experienced as supportive, some as challenging and some as both simultaneously. The result was a list of eleven elements. The supportive or challenging relationship within those elements (as shown in Figure 6) then formed part of the discussion for each element.

Table 19: Determining the elements of the experience of schizophrenia

SUPPORTIVE ELEMENTS	CHALLENGING ELEMENTS	FINAL ELEMENT
Use medication	Medication side effects	Medication
Maintain a supportive family	Family challenges	Family
Work in paid employment	Work stress	Work
Engage in meaningful pursuits		Stimulation
Use professional help		Mental health professionals
	Stress	Stress
Engage with other supportive people and groups	Difficult relationships	Social ties
	Stigma	Stigma
Live a healthy lifestyle		Lifestyle
	Physical health challenges	Physical health
	Health system barriers	The mental health system

7b   Evaluate essentiality of tentative elements to emergent structure

All elements shown in Table 19 were checked back against the original transcripts and brought again through the first steps of the PPM model to ensure that they remained essential. Then the emergent structure of support and challenge was interrogated from a number of different approaches to consider the essentiality of each element within.

Step eight: engage in psychophenomenological situational reflection

8a   Reflect on each element as recorded in language of participant

This step involved checking element labels as applied within the emergent structure to ensure continued reflection of the participant's voice and meaning wherever possible.

8b   Systematically examine each element; hope to capture essence of the experience

During the previous steps, and in particular Step 7, while the elements were being interpreted, a tentative idea of a deeper journey with schizophrenia was emerging. Many drawings, models, frameworks and ideas were created and discarded along the way during many months of reflection, to capture the essence of the experience of schizophrenia and the meaning of resilience within.

In addition to the eleven elements that had emerged from the first seven steps of PPM, there was a deeper experience of a journey in which the elements were encountered and within which the support and challenge dynamic was embedded. The experience of schizophrenia has been described as including feeling lost, struggling and striving and growing and within these experiences, the meaning of

resilience was embedded. Examples of emergent structures which are representative of descriptions of the experience of schizophrenia are shown in Figure 6: The support and challenge dynamic and Figure 7: The experience of schizophrenia.
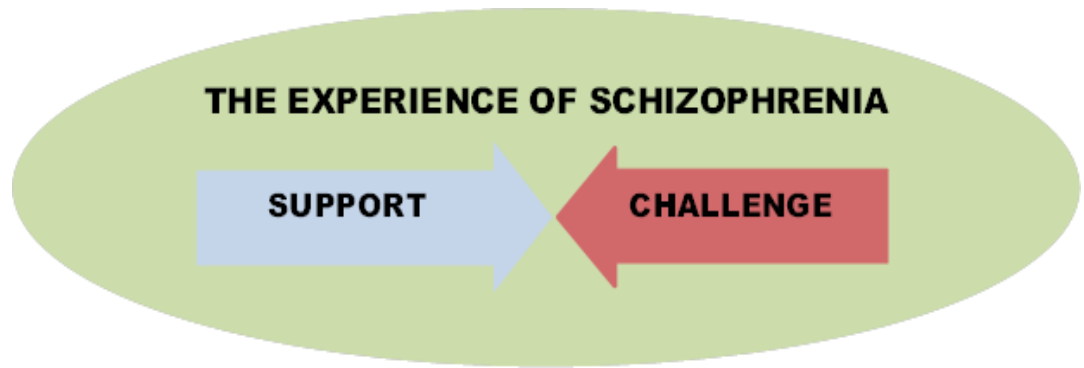
Figure 6: The support and challenge dynamic

THE EXPERIENCE OF SCHIZOPHRENIA	
GROWING	Make and maintain gains Feel a sense of control
STRIVING	Learn about self and illness Strive to overcome problems Take control Take responsibility
LOST	Feel pressure to change Feel like a victim of schizophrenia Feel lost DEVELOP SCHIZOPHRENIA

Figure 7: The experience of schizophrenia

STAGE TWO - TRANSLATION

Step nine: translate into the metalanguage of science

9a   *Transpose each essential element into metalanguage of discipline*

This step was used to reflect upon the methodological language within the work. However, one of the intents of the work was to retain accessible language and to represent the voices of participants. A balance was sought between these elements; participant's language was retained when it clearly identified the meaning of the element and was modified when clarification was needed. An example of this is using the word 'lifestyle' to sum up various participant comments that described this recognisable hypothetical health construct.

STAGE THREE - TRANSPOSITION

Step ten: determine fidelity (application)

10a   *Submit translation and transposition to independent judges*

At this step, a draft study map (see Appendix 6) was produced to show the questions that motivated the research, the main findings of the literature review, and the gap in knowledge, the study aims, the study method and the identification of preliminary essential structures. This allowed the research supervisors to take an overview and to examine the links and fidelity of the structures.

Step eleven: produce a paradigm of the experience (final identification)

The essence of the phenomenon of resilience was interpreted in this step. The eleven elements, the support and challenge dynamic, the interpreted experience of schizophrenia and the participant understandings for resilience were used in a process of reflecting, contemplating, intuiting, interpreting and producing the final essential structures, identifying the meaning and producing a paradigm of the experience. Results of this process are detailed in the findings in chapter four.

11a Integrate and synthesise judges' results into description

This was consistently carried out throughout the research as a part of the academic supervision process and in particular, the draft study map (see Appendix 6) was used to develop the work.

11b Submit description to practitioners for confirmation

Whilst not formally submitted, ideas, interpretations and emergent meanings were regularly discussed with clinical mental health nursing peers. In particular, the study map was regularly shown to colleagues to provide a forum for which to reflect, test and clarify my own thinking.

11c Accept confirmation as sufficiently probable

After approximately two years of collecting, analysing and 'living with' the data, a sense of clarity across the whole study emerged and created a sense of acceptance of the findings.

11d If there are serious objections, repeat the entire process

The process of academic supervision is one in which objections are regularly raised, discussed and dealt with along the way. In addition to this, Guba and Lincoln's trustworthiness criteria, as interpreted by Shenton (2004) were used to ensure additional rigour.

Step twelve: statement of limits

12a Clearly state the limits of the insight gained

This research used post-reflective interviews and as previously discussed followed a Heideggarian philosophy. The *truth* as to whether a situation actually happened was not being sought, but rather, the meaning of the experience to the person who had it (Polkinghorne 2007). Accordingly, the level of insight gained is from this perspective.

All research has limitations and whilst the sample size of 14 is acceptable for phenomenological research methodology, it does not produce generalisable results but instead, a 'sufficiently probable' outcome, according to van Kaam's step one, stage 11 process (Eppard & Anderson 1998). It was not the intent to generalise findings but contribute knowledge that most strongly relates to those who provided the experiences.

Finally, understanding the meaning of the experience does not automatically produce findings that are transferrable into clinical practice. Findings can be used though as a means of reflection. Reflective practice is paramount and a central component of contemporary mental health nursing practice (Farchaus Stein 2011).

Rigour in data analysis

In addition to using a validated model for data analysis, Guba and Lincoln (1985) identified a set of criteria for ensuring rigour within qualitative research. When these criteria have been met, the research is deemed to be trustworthy (Lincoln & Guba 1985; Merriam 1998; Shenton 2004). Criteria which contribute to trustworthiness include the credibility, dependability, confirmability and transferability of research findings (Lincoln & Guba 1985; Merriam 1998; Shenton 2004). The criteria are built into the research process from the beginning in order to be met at the end. These criteria are discussed below with regard to how they were considered within this research.

Credibility

The question of credibility can be summarised as the accuracy of a researcher's perceptions (Padgett 2008; Schwandt 2001). Assuring credibility requires the researcher to build in strategies to reduce the risks of presenting inconsistent or inaccurate findings from unintended bias or misleading representations of the data. Credibility is also linked to a continuous process that is integrated with theory and requires the researcher to continually assess assumptions, revise results, re-test theories and models and reappraise the given limitations. The process of ensuring credibility within this research has been carried out across the four stages of van Kaam's method of data analysis (Eppard & Anderson 1998). Further to this, peer debriefing with academic supervisors was also regularly used to ensure that the researcher's conceptual interpretation of the interview data is believable and congruent (Merriam 1998).

Dependability

Dependability requires the researcher to provide enough contextual and procedural detail to allow another researcher to repeat the study (Denzin & Lincoln 2011). Also, the details of data collection, analysis and theories of pattern can be used to confirm that the analysis and theory generation do in fact support the researcher's interpretations and findings (Shenton 2004). The processes of data analysis and theory generation have been overseen by the research higher degree supervisors of this study.

Confirmability

Confirmability relates to the ability of the researcher to produce objective findings from the data rather than to reflect the characteristics and preferences of the researcher (Lincoln & Guba 1985; Shenton 2004). Knowledge of the researcher's beliefs and attitudes about the area of interest can also shed light on where bias might threaten objectivity. Peer debriefing or supervision of the research project, including data analysis and generation of findings is a checking mechanism for maintaining objectivity. As suggested by Shenton (2004), audit trails were produced to improve confirmability (Shenton 2004) and examples of these have been shown within the discussion of how van Kaam's method of data analysis has been utilised. As described previously, I constantly immersed myself in processes of reflection and checking to ensure it was the participant's voices that were privileged and not my own.

Transferability

The transferability of the findings relates to who else the findings can be transferred to. Findings containing statements made about the meaning of resilience for people who experience schizophrenia may be transferrable to other people who experience

schizophrenia but would not be considered transferrable to someone who experiences another mental health condition, such as bipolar disorder or an affective disorder such as depression. Ultimately, the decision about transferability rests with the person using the findings and on how well the findings might relate based on the characteristics of their own wider population (Shenton 2004).

Further, transferability relates to how well the other criteria of credibility, dependability and confirmability have been met within the research process (Lincoln & Guba 1985; Merriam 1998; Shenton 2004). Therefore, there needs to be sufficient contextual and situational information within the findings to allow decisions about transferability to be made. Shenton (2004) also states that there needs to be sufficient richness and depth of description in order to compare circumstances. Through using a phenomenological approach, the voices of participants are captured and privileged in the language used to present the findings which may therefore resonate with others who share the experience. Furthermore, the PPM's attention to including the language of the discipline in findings makes it accessible to other professionals. Phenomenology is a rich, descriptive methodology and therefore the criteria for transferability have been addressed within this research.

This chapter introduced the research aim of examining the meaning of resilience for people who experience schizophrenia. The research paradigm was based on the belief that research involving vulnerable populations should be *with* them and not *about* them and therefore supported and adopted the consumer position of *nothing about me without me*. My professional education as a nurse, my nursing clinical role and my academic teaching role, all specialising in mental health brought a *mental health nurse* perspective to the research process. Without any personal experience of schizophrenia, the co-

creation of a shared understanding between the participants and me was required to correctly interpret and represent the experiential meaning of the phenomena under investigation. Phenomenology is a suitable method for investigating lived experiences and is becoming increasingly used in nursing inquiry. Heidegger's scientific phenomenology was adopted as the particular philosophy guiding the study. Ethical approval was received to personally interview fourteen consenting people who have lived experience of schizophrenia and this occurred at a time and place of their choosing. Van Kaam's psychophenomenological method was used to analyse the data.

The next chapter will present the findings of data analysis.

CHAPTER FOUR

FINDINGS

Introduction

This chapter outlines the main findings from the phenomenological analysis of the 14 participant descriptions using van Kaam's Psychophenomenological Method (PPM) (Eppard & Anderson 1998). Analysis of participant data resulted in the main finding of the meaning of resilience for people who experience schizophrenia. The meaning of resilience is embedded within the struggle of striving to overcome the challenges brought by schizophrenia and live a fulfilling life that is about more than just managing the illness.

Initial analysis of participant data revealed eleven elements, which were; medication, family, employment, stimulation, mental health professionals, social ties, stress, stigma, physical health, the mental health system and healthy lifestyle. The elements emerged through participants identifying their importance to the meaning of resilience. Whilst participant descriptions often suggested an overlap between elements, they are discussed as separate elements due to participants describing different challenges related to each element that were important to the experience of the element.

There was an underlying structural element of support and challenge, with some elements being experienced as both supportive and challenging. The experience of both supportive and challenging aspects within the same element created a dynamic whereby participants described disengaging with the support side when the associated challenge was too great. As a result, participants needed to overcome the challenge in order to be able to 'use' the support.

The way in which participants overcame challenges is characterised by the word *striving*. The energy of *striving* flowed from firstly dealing with one challenge to then being able to deal with other challenges along the journey with schizophrenia and also to then cope with other challenges that were not directly related to dealing with schizophrenia. *Striving* to cope was demonstrated within the descriptions provided by participants that typically began with their early illness experiences and remained a constant part of everyday living. The meaning of resilience for participants is inextricably embedded within striving to overcome challenges.

This chapter describes the elements within the experience of schizophrenia; the support and challenge dynamic, overcoming challenges in the journey with schizophrenia and the meaning of resilience within these experiences for participants. Each element will be more fully discussed in chapter five.

Elements

Table 20 lists the elements that emerged during step 2 of the PPM wherein meaningful structural elements were noted, differentiated and recorded. The specifics of each element as they arose from participant interviews are also discussed.

Table 20: The elements of the experience of schizophrenia

ELEMENTS OF THE EXPERIENCE OF SCHIZOPHRENIA	
Medication	Stigma
Family	Lifestyle
Work	Physical health
Stimulation	Mental health professionals
Stress	The mental health system
Social ties	

Medication

Medication was described as a challenge in the descriptions of early illness, mostly related to undesirable side effects (participants 3, 4, 5, 6, 10, 11, 14). Medication challenges were identified by participants as dribbling, drowsiness, sedation, difficulty concentrating, excessive weight gain and increased blood sugar levels. Participants described that during the early phase of their illness they felt that medication side effects could not be tolerated and that medications were not necessary. Participants described what they termed "going off" their medications and then experiencing episodes of psychosis. After repeated episodes of ceasing medications and experiencing an exacerbation of their illness, participants came to the realisation that their solution for the side effects (cessation of medication) was far worse than the problem (side effects). The role played by medication, described as bringing "better thoughts" and "keeping a stable, even keel" was realised and accepted as that which fulfilled a supportive role.

A period of experimentation "to get the right medicine" followed for many participants. This too, known as "medicine juggling" resulted in illness episodes; however participants indicated that it was different, that they were trying to get the medication right, with the support of health professionals, rather than getting off the medication and disengaging with support. Participant eight pointed out that "*using* medication is different from *taking* medication". Taking control of the decision regarding which medication is most effective, and then deliberately *using* that medication to control symptoms contributed to what participants described as "achieving a desired state of living ... finding the least worst medication and accepting its side effects" *(P8).*

Analysis and subsequent phenomenological interpretation of the full range of descriptions captured within the element of medication resulted in the following

summary statement: using medication is a choice and it comes with major challenges, seek to understand and overcome them.

Family

In the early stages of the illness, participants initially viewed family members' efforts as challenging; for example when family forcefully advocated for treatment or insisted that participants accept that they were ill and do something about it. Participants described how families often assumed a "caretaking role" and provided practical support when illness prevented them from meeting their own needs or carrying out their responsibilities.

Participant thirteen described how seeing self as a victim of schizophrenia was a dangerous perspective to have because it led to staying trapped in the illness role. Participants one and five in particular described family as becoming comfortable with this dynamic and how this could lead to family members being obstructive to the person's efforts to move out of the illness role. Challenges from family were described when some participants changed their role from the person with a mental illness being *cared for* to the person who assumed responsibility and took risks to achieve a better quality of life. As participants started to gain control, they described the need to actively maintain the support and goodwill of family by not being passive recipients of care but also by *caring for carers* and giving care back. By doing this, participants felt that they were maintaining a balanced relationship. Despite some challenges, particularly when the participant was in the early days of their illness, the majority of participants described the role of family as supportive in nature. Family became increasingly more valued as the person gained insight into their illness. Analysis and interpretation of the full range of descriptions captured within the element of family resulted in the following

summary statement; family both supported and challenged me, however, it's important to trust others and to care for my carers.

Work

Working in paid employment was considered highly desirable to maintain self-esteem as well as maintaining some financial independence   Work was, however, described as being highly stressful, and the ability to work was heavily impacted upon by medication side effects. Unwanted symptoms of drowsiness and sedation caused an inability to focus made it difficult for participants to actually concentrate and stay awake while at work.

Of the five participants who were working in paid employment at the time of the interviews none was still working in the same occupational capacity as they had been prior to the onset of their illness. Participant ten described having to significantly "downgrade employment expectations" to be able to work at all. Having to compete for work against people who did not have a mental illness was described as being "pushed into disability-specific job roles which pay very low wages" (P 10). These roles were also described as those which "don't support independence" and actually "foster dependence on disability services" (P 10).

Additionally, high levels of anxiety, stress and problems with coping with other people and their attitudes towards the way a person with schizophrenia may behave in the workplace was described as very challenging. There was a feeling of being stigmatised and therefore the elements of work, stress and stigma overlap. Some participants described how they maintained their employment at a casual or part-time level that allowed them to cope with the stress of working and to maintain wellness. Others

described being in a process of working their way towards more fulfilling and responsible job roles, albeit in entirely different areas to their pre-illness occupations. There was mention of a shift into more help-oriented work, such as social work type roles as opposed to previous business or financial occupations and this was described as being surprisingly fulfilling and rewarding, despite receiving low rates of pay.

Participant twelve described using what they believed was their resilience to undertake a course of study and to take up a supported work role. This participant then left the supported situation and achieved employment, with their new skill, in the open job market. Participant twelve indicated that this took several years to achieve while simultaneously addressing the challenges and building support for the future.

Stimulation

The element identified as stimulation was seen as one of the greatest challenges in the journey with schizophrenia. Having "something to do" was deemed necessary in order to avoid "going crazy" (P 13). It was also a way to experience pleasure as well as contributing to a sense of achievement. Participants described many pursuits as being both stimulating and rewarding. Such activities included volunteering, studying, playing musical instruments, recording and mixing music, building models, fishing, gardening, writing, art, sewing and general craft and also re-building a motorbike. What came through strongly during the interviews was that on commencement, these activities were experienced as extremely challenging, particularly with trying to focus and concentrate on the tasks in order to learn what they were about. Several participants strongly stressed the need to "just keep on trying" (P 10; P 13), "try again and again" (P 1; P 7), and to "just keep getting back up after a fall" (P 1; P 11), because it eventually got easier and a sense of achievement as a result of being stimulated did arrive. Being able

to overcome the challenge and be successful at one thing led participants to try new things and ultimately to developing a range of interests and pursue numerous activities. Analysis and interpretation of the full range of descriptions within the element of stimulation resulted in the following summary statement: community connection brings a sense of belonging - find an outlet, hobby or exercise and try, try and try again, you will become good at it.

Stress

The element identified as stress was described as being an ever-present challenge. Participants elucidated how their perceptions of stress and reactions to stress changed through the course of the illness experience. Initially, upon feeling stressed and unable to cope, participants sought out family members to help "sort out the problems" (P 5; P 10; P 4) causing stress. Participants described not being able to cope, and sometimes this led them to having a relapse of their illness. However, when stress was being caused by something that was desirable, such as employment, participants described how they felt it was necessary to "learn to cope" (P 1; P2; P 3; P 4; 5; P 7; P 11; P 12) . Learning to cope was initially achieved through seeking out professional help. However, participants then described how they gradually learned to take over management of the stress by developing personal strategies such as positive self-talk, the use of symbolic prompts such as reminders to calm down and resume control and by using meditation. Some participants deliberately structured their lives in ways that helped them to avoid or minimise stress, which in some cases limited their social options. Participant ten articulated the view that not every stressful situation is to do with the illness, and it was a relief to realise that "it's just normal life stress that's happening". Analysis and interpretation of the full range of descriptions captured within

the element of stress resulted in the following statement; feeling stress is normal and is not always related to the illness, learn to handle it.

Social ties

Socially engaging with people and with groups was a two-edged sword; valuable for learning from others who know how to live with schizophrenia or who can provide some form of support in the early stages, but also associated with stress caused by the actions, attitudes, expectations and pressure of other people. Some participants valued mixing with people who also have a mental illness. However, other participants avoided it as they described the relationships as difficult and stressful. Participants who said they avoided mixing with other people who also had a mental illness did so to avoid making the mental illness the major issue in life. Difficult relationships with others within social contexts led some participants to avoid socialising altogether. However, by choosing not to mix with others they knew they were destined to live a more isolated life.

In the early stages of their illness, participants described others as exerting pressure on them to change, and when their well-meant advice was not followed, this sometimes led to the friend or family member disengaging. It seemed necessary for participants to regulate exposure to people in social situations; this was done according to the individual's ability to cope. As a result some participants had many friends and belonged to many groups and others had one supportive friend or relative and generally avoided stress by avoiding others. There was a state of acceptance around these reduced social circumstances because it was seen as a necessary part of maintaining wellness.

Stigma

Stigma was associated by participants as feeling a need to adopt the *role* of schizophrenia once the label had been applied and to start acting like a 'schizophrenic'. Resilience was the word participants used as being important in the face of stigma. It was also linked with gracefully understanding and accepting that other people make judgements about people with schizophrenia based on their ignorance. Not responding or reacting negatively to others' ignorance was described as a very difficult but necessary attitude to adopt.

The meaning of resilience was linked with the need to take control and to take action to pull away from staying in a victim attitude as a result of feeling stigmatised. Analysis and interpretation of the full range of descriptions captured within the element of stigma resulted in the following summary statement; accept that stigma is part of the experience, don't take on the mantle of stigma but instead try to understand it.

Lifestyle

Living a healthy lifestyle was seen as important for maintaining resilience and was described as being achievable through eating well, sleeping well and behaving well. Ways that participants indicated they could do this included; drinking water, eating fresh food including lots of fruit, not smoking, not drinking alcohol, meditating and having a faith. Continuously working on the physical and emotional state was described as necessary for living a healthy lifestyle, which in turn contributed to maintaining resilience and a stable state of physical and mental health.

Participant twelve indicated that their resilience was invoked through striving to quit smoking cigarettes and that the feeling of success and control that they felt when they

were successful, led to quitting drinking alcohol as well. This participant then used their new found power of resilience to change diet, to start exercising and to overhaul their lifestyle to one that supported how they wanted to live. Participant twelve stated they had continued this pattern throughout the past ten years and had added playing the piano and playing the violin to their repertoire.

Physical health

Participant ten discussed the physical nature of mental illness *'the delusional state [...] people that haven't been there that don't understand, it's so physical, it's the physical energy, your heart aches, you feel hungry, you ache all over, you say goodbye to your mind'*.

Physical health problems described as being of particular concern were obesity and also the serious fluctuations in mental state attributed to the menstrual cycle for female participants. Being obese was described as *unhealthy* and *not OK*. One participant pointed out that it is wrong to accept or normalise a state of being overweight. The menstrual cycle was perceived to have a causal relationship with episodes of psychosis by female participants and they found that this problem ceased with menopause which was described as a welcome relief by some of the participants.

Physical activity was used as a doorway to change. Participant ten described experiencing an awakening of their mind, which was accompanied by the urge to get on the kitchen floor and do one push up and one sit up, which they did, followed by ten of each the next night and then they went onward, striving to achieve increasingly higher levels of physical activity and fitness.

The mental health system

When a person has a mental illness they invariably become part of a health system due to the need to access treatment and to learn how to manage what is happening (Barker 2009a; Frese, Knight & Saks 2009). Health systems are complex entities that, because of their size and nature are not particularly focused on the individual (Blendon et al. 2003). Experiences with mental health services provided within the health system were described by participants as challenging. This was particularly considered so with regard to in-patient admission procedures. Refusal to admit a person to an in-patient unit when the ill person believes that admission is necessary to manage their deteriorating mental state was a matter of some tension. Several participants described experiencing this failure to gain admission to an inpatient unit when they believed they needed it. In some cases participants described how they had to rely on the strong advocacy of 'sane' family members to access what they felt were much needed services. Participants identified how they overcame what they described as "health system barriers" by themselves, by learning how to more effectively navigate and use the "system" to better meet their needs. Other associated problems were the closure of services, being discharged from receiving services and experiencing frequent changes of key workers. These challenges were described in some cases as causing a relapse to illness.

Mental health professionals

Seeking professional help and receiving advice in the early stages of illness was not initially fully welcomed despite participants indicating that there was respect for particular mental health professionals. For participant ten, stigma was taken on as a mantle as a result of seeking professional help and being advised by their psychiatrist to

'never tell anyone' that they are *'schizophrenic'*. Mental health practitioners were also described as being patient, and just going along beside an often unwilling person but nonetheless remaining supportive while participants *'ignored'* their advice.

Picking up the phone and being able to access a mental health professional who could advise on coping strategies or medications at times of stress or when symptoms were increasing was particularly valued for learning how to cope, for averting an "episode" and for maintaining wellness.

The relationships participants had with mental health professionals also changed over time. Participant eleven embarked into a paid work role within the mental health field and was no longer able to obtain 'service' from their previous case manager. This participant expressed that his previous case manager could not adapt to them now being a peer in the workforce and did not know how to communicate this in a professional manner. This change in relationship challenged them and required them to organise new supportive relationships with other mental health professionals for the sake of their own wellness. Early in their stories, participant descriptions suggested that they felt 'managed' by mental health professionals but in the later stages of their descriptions, they described 'using' professional help out of choice. These terms are now subject of debate in the literature with consumers arguing they are not 'cases to be managed'. An emerging model of self-managed care has begun to address many of the consumer concerns arising from being regarded as being a 'case to be managed' (Cook et al. 2012).

From participant descriptions of the meaning of resilience for them, eleven different and yet overlapping areas of experience were identified as meaningful and these were extracted and labelled as elements. The elements were medication, family, work, stimulation, stress, social ties, stigma, lifestyle, physical health, the mental health system and mental health professionals. The interpretation for each element has been discussed, and within these quotes from participant descriptions have been used to provide connection with the essence of the experience. The next section of this work will discuss the deeper interpretation of the way in which the elements are woven within the experience of schizophrenia.

The support and challenge dynamic

Appreciating that individual issues, and the elements that they have been interpreted within, are not easily separated from one another, contributes to understanding that living with schizophrenia is a personal journey and that life circumstances do not easily fall into single categories. As highlighted earlier in this chapter, many elements were simultaneously experienced as both supportive and challenging. Although participants described some elements in purely supportive or purely challenging terms, the duality of both support and challenge within single elements, suggests that participants experienced tension between the supportive and challenging aspects, albeit they are nested within the same experience. Table 21 lists the elements and highlights whether participants experienced or described them as supportive, challenging or both.

Table 21: Supportive and challenging elements

ELEMENT	SUPPORTIVE OR CHALLENGING
Medication	Both supportive and challenging
Family	Both supportive and challenging
Work	Both supportive and challenging
Stimulation	Supportive
Stress	Challenging
Social ties	Both supportive and challenging
Stigma	Challenging
Lifestyle	Supportive
Physical health	Both supportive and challenging
The mental health system	Challenging
Mental health professionals	Both supportive and challenging

The meaning for resilience for a person who is living with schizophrenia emerged as a result of the tension that existed between the support and challenges within a single experience and the *'striving'* to overcome them.

Resilience was thus embedded within 'striving'. For example, needing medication to achieve relief from symptoms but not being able to tolerate the serious side effects caused a dilemma. Participants described being overwhelmed by challenges and then disengaging with supportive aspects, which in the case of medication, resulted in participants discontinuing it and then becoming vulnerable to the illness. In coming to realise the need for medication as a means of getting symptoms under control, it 'forced' people to take responsibility for "sorting out" and overcoming the challenges caused by medication side effects. Participant's spoke of feeling how important it was to overcome the challenges through learning to cope with them so that they could access

the supportive side of the element. The word *striving* captures and typifies the energy embedded in participant descriptions of overcoming challenges; that is resilience is being able to 'strive'.

The dynamic of *striving* to overcome challenges by learning how to deal with them and also by accessing supports and other resources in the process, is synchronous with the understanding of resilience that was gained from the wider review of literature for this research. The meaning of resilience within this study is not about the tension caused by the dual nature of both challenge and support within some elements, but rather the way in which the desirability of something supportive leads to the decision to take on the associated challenges and to strive to overcome the problems. Overcoming the challenge required ignoring the temptation to feel and act like a failure and instead to keep trying, to persist and strive to overcome problems. The way in which striving was involved with overcoming the specific challenges has been analysed and the interpretation of this is described next.

The experience of schizophrenia

Participants described particular attitudes they held at various times, decisions that they made and actions that they took to deal with the challenges brought by living with schizophrenia. They also talked about how to develop and use support.   Within this journey, participants experienced changing views of themselves in relation to their illness, such as self being lost within the experience of schizophrenia, self as struggling to deal with the illness and the self as separate and feeling a degree of control over the illness experience. These changing views were like a thread woven within actions taken to change their lived experience. The journey with schizophrenia was characterised by experiences such as feeling lost, feeling like a victim of schizophrenia, struggling with

challenges, feeling pressure to change, deciding to change, taking responsibility, taking control, striving to overcome challenges, learning about self and illness, feeling a sense of control and making and maintaining gains. The meaning of resilience was embedded within experiences of falling over, getting back up, not seeing it as failure, trying, trying and trying again, striving and achieving change.

Early in the illness experience, participants described how they felt that they did not know what was happening to them. Family and friends became concerned and tried to communicate this; however it was only grasped in situations where there was a deeply trusting relationship. Contact with health services did not provide clarification, often because of multiple diagnoses being given and even when the diagnosis was made clear, there was very little accompanying information to provide clarity of the situation they were in and the future they faced. This was also complicated by the impaired insight caused by overwhelming illness symptoms. Treatment (medication) delivered undesirable side effects and some professionals unwittingly delivered stigma. Participants described having little idea of how they had become ill or how they would get better. The natural conclusion was to feel lost, to become a *'schizophrenic'* and to adopt the role of being a victim of schizophrenia. Participant ten used the metaphor of cotton wool to describe their experiences of being lost within the illness *... and there was cotton wool in every direction that you wanted to see so I kept falling back into [hospital] (P10).*

As things continued to unravel, family and friends began to exert pressure to change. Some participants described a feeling of self-generated internal pressure to "get a grip" on the situation and to change it. A period of struggle followed, often lasting months or years, to gain a sense of what was happening and to begin to separate self and illness.

Once this separation had been made, and the self was again identifiable, participants were able to start taking responsibility for dealing with the illness aspect. Some participants experienced this as an awakening and described it as a pivotal turning point towards taking responsibility and for others, the moment just arrived; one participant said "I just snapped out of it". Participant one described taking responsibility as "a process, someone can't just show it to you". A mixture of *acceptance*, and being *willing and not wilful* was suggested as being necessary to begin to grasp the concept of taking responsibility.

Taking responsibility was followed by descriptions of taking control and taking action. Actions that participants described included; learning about schizophrenia, learning about the 'self', learning to cope through using professional help and linking up with support such as groups and peer-support networks. A period of gain and growth was then described; gaining stimulation and pleasure from taking up hobbies, taking up responsible roles, pursuing education opportunities and going back to work.

Three structural elements can be seen within the changing views of self that were woven through the experience of schizophrenia; lost, striving and growing. From the early experience of feeling like a victim under the control of schizophrenia, participants described how they then recognised the self as separate, had striven to gain control of the illness and had then exercised much greater control over living with schizophrenia. This, said participants, enabled them to lead a life that was stable, manageable and largely under their own control. These three structural elements and the experiences that characterised them are presented in Figure 8, the experience of schizophrenia.
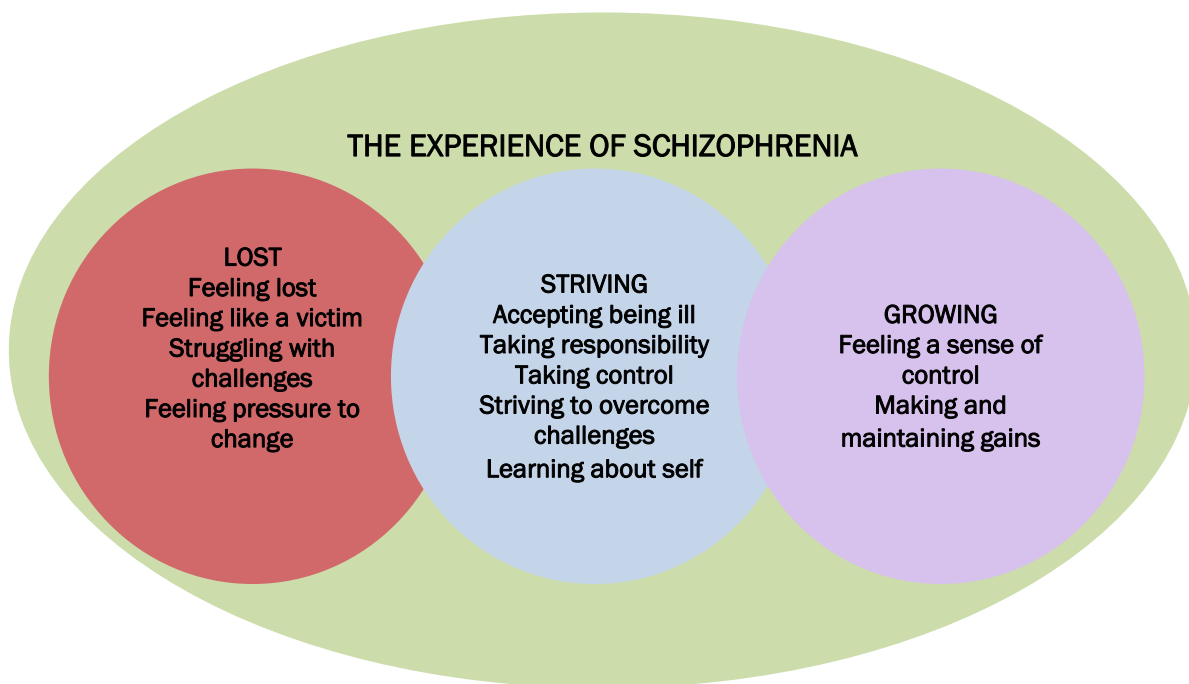
Figure 8: The experience of schizophrenia

This understanding and conceptualisation of participant's experiences with schizophrenia contributes to understanding the meaning of resilience for people who experience schizophrenia.

The meaning of resilience within the experience of schizophrenia

The meaning of resilience for people who experience schizophrenia emerged through thoughtful synthesis of the elements; the support and challenge dynamic, and the way in which challenges were overcome within the experience of schizophrenia. A summary statement resulting from the synthesis is presented in Figure 9. Many of the original words provided by participants in their interviews have been used to represent this meaning.

> *Resilience means adopting an attitude of striving to overcome the severe adversity caused by the experience of schizophrenia. The process of striving enables the person to learn about themselves, the effect of the schizophrenia illness on them, and how to manage it in the context of the life they want to live. Striving to overcome schizophrenia involves struggle, including repeated backwards steps and during this, the person seeks out and uses supportive people and resources. The process of seeking out and using support also comes with challenges and resilience emerges from the process of competently overcoming these, in the quest for improvement. The person then seeks out new challenges and experiences and grows life in ways unrelated to just living to manage the illness.*

Figure 9: The meaning of resilience within the experience of schizophrenia

The challenges faced by people living with schizophrenia are important to recognise and understand. If the challenge is associated with something that can also be supportive, such as medications and their side effects, the person is motivated to strive to overcome the challenge in order to use the support. Striving to overcome challenge is central to the meaning of resilience. The experience of schizophrenia begins with a sense of loss during which the person can feel like a victim and really struggle with the challenges. This struggle is met with pressure to change, either from self or others. It is necessary to accept being ill, to take responsibility, to take control and to strive to overcome the challenges, which includes learning about self and illness. These attitudes and actions lead to feeling a sense of control, the ability to make and maintain gains and being able to grow life in ways other than just living to manage schizophrenia.

This chapter presented the findings as a result of van Kaam's systemic and analytical approach to data interpretation. The elements that were discussed were identified as a result of interviews with people who have lived experience of schizophrenia. Living with schizophrenia brings many challenges that are in addition to the normal stresses and strains of everyday life (Mueser & Jeste 2008). At times, the challenges can be of such magnitude that they obscure the person's sense of self and remove the ability to grasp the reality of living with schizophrenia. This research has found that for people who are living with schizophrenia it is necessary for the person to strive to learn to overcome the challenges brought by the illness and the meaning of resilience is located within that quest for improvement.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter builds on the findings presented in chapter four and compares them with existing literature. The aim of the research was to phenomenologically interpret the descriptions provided by fourteen people diagnosed with schizophrenia to find a meaning for resilience within the experience of schizophrenia. Discussion of findings has been organised in a manner that reflects the findings: the order of the meaningful elements that were identified, the dynamic that was interpreted between the supportive and challenging aspects within many of those elements, and how these sit within the longer journey with schizophrenia. These three areas contributed to the meaning for resilience for a person who is living with schizophrenia, which will be the final part of the discussion. Throughout the discussion, all findings have been compared with the wider literature. Within this, many of the tables and figures presented within the findings chapter have been repeated for ease of reading.

As previously discussed in the Research Design Chapter, this work is being presented with a strong emphasis on actively listening and interpreting, rather than re-interpreting and re-presenting the participant's voices. The reason for this is well stated by Shotter (1981, p. 278):

> *Authoring one's own experience is a basic human right. In a moral world no one but the person in question has the status, the authority, under normal conditions, to decide what his/her experience means to them.*

Therefore, as this work is interpreting the meaning of experiences as described by those who have had the experience, direct quotes will be used within the discussion to demonstrate the meaning.

Elements

Eleven elements were interpreted from the systematised approach to analysis of all participant data. These are identified in Table 22.

Table 22: Elements of the experience of schizophrenia

ELEMENTS	
Medication	Stigma
Family	Lifestyle
Work	Physical health
Stimulation	Mental health professionals
Stress	The mental health system
Social ties	

Each element in Table 22 will now be described in detail, compared with existing literature and then discussed.

Medication

Participants indicated that medication has a very important role as an element in what contributed to the meaning of resilience for people who experience schizophrenia.   It was identified as both highly supportive but also as highly challenging. Participants described how coming to terms with medication was considered an evolving journey that often starts with feeling pressured to take medication but not doing so easily or consistently, and one that ended up with the participants coming to the realisation that

medication is an essential part of them living with schizophrenia; compliance was then a matter of choice. Participants spoke of this realisation as one which is inclusive of understanding and accepting the need to take medication, choosing to take medication, dealing with the side effects, gaining knowledge about medications and participating in the decision about which medication suited their own particular needs.

Participants initially struggled with the idea of taking medication:

> *I wouldn't take medication. I refused to take medication. (P1)*

> *I wouldn't accept that I had an illness and I just wouldn't accept it and people persisted and they insisted that I take my medication. (P3)*

Some took medication because they felt forced to:

> *They said are you going to take this [medication] syrup and a tablet and you could see the wards men all line up if I didn't take the tablet I assume a 5 person take down and I'd be given an injection. (P9)*

> *I almost bet if I became unwell I'd be non-compliant. No one wants to lose their freedom. Mind you I was non-compliant every time, the police escort and the whole bit. (P10)*

Or, they didn't know that they needed to take medication continuously:

> *Unfortunately the hospital hadn't told me to stay on the tablets. I had to learn that the next few years. (P6)*

In a study conducted in Switzerland to explore attitudes towards medication adherence for 150 consumers living in the community who were diagnosed with schizophrenia, Beck et al (2011) found a direct negative relationship between medication problems and non-compliance for 40 per cent of the cohort. Within this 40 per cent were people who chose not to take medication because they perceived it as ineffective. Parashos et al (2000) undertook a mixed method study in Greece and examined the reasons why twenty nine people diagnosed with schizophrenia and living in the community decided

not to take anti-psychotic medication. Findings revealed that 50 per cent of the reasons for non- compliance were related directly to the side effects of the medication being taken, and lack of knowledge on the illness, including the course of illness and how to manage it. Meehan, Stedman and Wallace (2011) interviewed 238 consumers in focus groups in Australia to identify and rank the key side effects that have the most impact on consumer functioning, with a score of five representing the highest impact. Sedation and tiredness carried the highest impact, with a score of 4.6, followed by weight gain, with a score of 4.3 and difficulty thinking and concentrating with a score of 4.2.

The participants within this study also identified medication side effects as a major challenge:

> *You talk about luck, I've been on medication where I've been so groggy and I've driven all around the place and I've survived and I haven't hurt anybody and I just think that so lucky. (P3)*

> *I wasn't able to maintain the job. I think that was mainly through the medication also at the time I found it hard to think properly and stay awake during the day. (P11)*

> *I went on [medication] for six years and it wasn't very good and I nearly ended up with diabetes, I got very fat, my blood sugar started to rise and my psychiatrist and doctor became alarmed so after 6 years I have gone back to [medication]. (P13)*

> *When I went onto the [medication], and I put on quite a bit of weight as well … I was huge, if you weren't on a diet the whole time the lady doctor even told me that I have a weird body because I put on so much weight. (P5)*

In the Meehan et al (2011) study cited earlier, consumers indicated that maintaining a balanced lifestyle, healthy eating and sleeping routines as well a positive outlook were among the strategies employed to manage medication side effects. These are strategies which were also employed by participants in this study and were described as

being important for maintaining resilience and a stable state of physical and mental health.

Various participants in the current study described periods of coming off the medications, sometimes prompted by health professionals and sometimes accompanied by relapses to psychosis and consequent hospitalisation.

> *I was OK until I went off the medication. The Dr took me off it because he said I was doing so well that I didn't need it and I thought OK I'll give it a go then I got sick and I had no help to get better I didn't sleep, I cried and I did what I had to do for the kids. That was very, very hard. I knew I needed medication when I got sick again. (P4)*

> *I had come off the antipsychotics they had prescribed for me because the side effects were very unpleasant [...] I decided to try and battle the symptoms on my own [...] then it all snapped in one go [...] I was in hospital on the other side of a prescription. (P10)*

A study of 1,346 people in Spain conducted by San-Molina et al (2011) to identify the reasons for relapse in people with schizophrenia attributed 67.1 per cent of admissions to medication non-compliance. For some participants in this research, the experience of repeated psychotic episodes led to them understanding their illness and the acceptance of being ill. It also contributed to their awareness that medication was needed to stabilise the symptoms of schizophrenia and to stay well.

> *Acceptance, be willing and not wilful that helps people to grasp how to approach their life now that they have a mental problem [...] getting the medication for schizophrenia is the first step, that was the big step, I had to go to gaol to realise that I needed the medication full time. (P1)*

> *I said to myself I'm sure I need medication. (P6)*

> *I needed that [medication] to be able to function day to day; I did it out of choice. (P4)*

> *I have been very consistent in taking my medication. (P13)*

For a long while I went through a stage where I wouldn't take medication I refused to take medication and my local GP was patient. People insisted people cared enough to insist that I take it and that's just been such a help, medication, such a help. (P3)

In the Beck et al (2011) study mentioned earlier, researchers found a positive relationship between a person being aware of their illness and the belief that medication is necessary. This is often referred to as insight (Rüsch et al. 2009). Once the need to take medication had been realised or accepted, participants described it as important to learn more about the medication they took. This increased their understanding and enabled them to make informed choices.

Read about the different medicines, what they do, [...] so that you can make informed decisions. (P13)

I used to beg him all the time to please if anything new comes in, any new antipsychotics would you please try them on me, please don't ever give me [medication] again. He tried when a couple of new ones came and I couldn't tolerate them. Dr [...] actually gave me a lot less medication and I got better [...] I'm having no side effects. (P5)

He [the psychiatrist] wanted me to go on the new tablet, and I read the brochure and thought this sounds terrible so I said to him look I want to go back on [medication] I said if I get tardive dyskinesia even then I would not go off [medication], you know. [Medication] has always agreed with me. Life is full of bad things and if I get tardive dyskinesia I am just going to have to lump it. (P6)

Participants described coming to realise that medications formed *part* of the solution, rather than being *the* solution:

I realised at that point as well, the answer wasn't just in medication, you had to do your homework. (P10)

One participant advised that they had decided to come off medication through a deliberate, planned and collaboratively managed approach:

I've been off medication for about 3 months. The last few years I was on a really low dose. The doctor was managing me coming off. It took a long

> *time, six months, then another six months. I still see the Psychiatrist and*
> *my doctor to get checked out. (P12)*

Another participant summed up how attitudes and behaviour regarding medication were apt to change over time. This participant pointed out that they don't 'take' medication; rather that they choose to 'use' medication as part of the management of the illness. Participant eight also provided an insight into their journey with medication:

> *There's no secret to survival, only finding the least worst medication and*
> *accepting its side effects. I see medication now as life-saving literally and*
> *I've gotten more used to the side effects [...]. It's certainly better than*
> *being dead or psychotic. It's unfortunate to have to take medication but*
> *I've discovered it doesn't necessarily mean that I can't still lead a*
> *successful and productive life. (P8)*

Medications are described as the cornerstone of treatment for schizophrenia (Tandon, Nasrallah & Keshavan 2010; Usher, Foster & Park 2006) and have been found to reduce the overall symptoms and risk for relapse (Tandon, Nasrallah & Keshavan 2010; Usher 2001). However not all medications work for all people and considerable experimentation and tenacity are required to find the right medication for each individual. A study by Swarbrick and Roe (2011) conducted in the United States of America to investigate factors influencing the medication choice of nineteen people diagnosed with mental illness found that an authentic dialogue between the medication prescriber and the user is needed to identify and consider the personal factors that are likely to influence medication adherence. By having such a dialogue the consumer felt as though they had more control over medication decisions. This degree of autonomy was seen as important for being able to actively engage in the process of identifying the right medication to reduce the challenges of side effects and implicit within this, is achieving an education on the various medications available.

Pat Deegan, an American psychologist and researcher who describes herself as a consumer professional and writes about the experience of schizophrenia, describes *learning to use* medications as taking an *active stance* (Deegan 1996). Gottesman and Hanson (2005) described a link between anti-psychotic medications and resilience, stating that the medications have an anti-inflammatory effect which reduces the inflammation of tissues caused by stress and prevents the stress-related erosion of an individual's ability to respond resiliently to challenges.

Family

Family was another element identified. Participants strongly valued their family and the role family played in supporting them, however particular challenges inherent in accepting family support and which were necessary to deal with in order to maintain the support were reported. Family, as identified in the interviews, were the participant's immediate family; parents, partners, siblings and children.

Research carried out in Switzerland in the 1940s and 1950s theorised causal links between parenting style and the development of schizophrenia (Bleuler 1978) and despite the fact that the theories were never found or validated, they held considerable power within psychiatry until the 1970s (Morris 2012; Neill 1990). The theory was that 'schizophrenogenic mothers' were dominating who controlled all of the child's activities, who shaped the child according to a set of rigid norms and who isolated the child and stifled growth while believing that the child was a personal possession (Bleuler 1978). Fathers, at the same time, were considered to be either weaklings who held no personal influence or control over their families or to be tyrannical, authoritarian or cruel (Bleuler 1978). The consequence of these early beliefs was the blaming stigmatisation of the family of a person who developed schizophrenia. The

legacy of this was that when a biological causation for schizophrenia was proposed it was wholeheartedly embraced by families desperate to remove the mantle of blame and the new hope for schizophrenia was entrenched within a biomedical model of treatment that placed almost no emphasis on family involvement.

There is a paucity of published literature on the perception of consumers with regard to the support provided by relatives. Fleury et al (2008) analysed the support provided by the relatives of 186 consumers in Canada. One of the study's aims was to ascertain which needs were best served for consumers who were living with or who had regular, supportive contact with their families. Findings were that consumers with supportive family relationships in place had more assets, more varied sources of income, more regular consumption of medication and significantly shorter hospital stays as well as enjoying more clinical stability. Pernice-Duca (2010) determined which dimensions of the family support network were most important to the recovery process according to the consumer's perspective and identified that the support and reciprocity of family members are important dimensions of a personal support network.

A recent Cochrane Collaboration review of 21 studies, including 53 randomised controlled trials conducted by Pharoah et al (2010) to assess the results of family intervention when a family member has schizophrenia, also identified that supportive families play a role in decreasing the frequency of relapse, reducing hospital admission and encouraging medication compliance. Emotional problems within families are linked with increased stress and relapse (Pharoah et al. 2010) and therefore the challenge of difficult family relationships is one that needs to be overcome in order to achieve and maintain a state of wellness. The Fleury et al (2006) study from Canada also identified a larger percentage of family psychiatric problems in the group of

consumers who were living with family. Furthermore, a study carried out by Guada et al (2012) to test how family factors impacted on the functioning of a family member with schizophrenia in 93 African American families identified that greater amounts of family contact had a significant relationship with better functioning except where there was family dysfunction, which then had a negative relationship to consumer functioning.

Participants within this study identified that their family largely acted as advocates for them receiving much needed treatment. They also provided motivation to attend to responsibilities or took care of them when the person wasn't able to. They had a role in raising insight and for calling attention to warning signs for mood problems or illness symptoms. Problems within the family unit were described as causing serious stress and were linked with relapse to episodes of illness and other very serious problems such as long term homelessness.

In the early stages of the illness journey, it was the family who advocated strongly for help:

> *I tried to get into [hospital]. I went to outpatients and one doctor said that it wasn't a holiday house and he wasn't going to admit me, I went there two or three times, I went to [another hospital] for help and really they didn't want any part of me because they wouldn't admit me and then my brother in law was [...], an officer in the [...]force and he came with me and I don't know what he said to the doctor but he called the doctor away out of the room and then the doctor admitted me to [hospital]. (P4)*

> *I'd been up in Cairns and got sick up there and then mum and dad flew up and brought me back because they just sensed something was wrong with the phone calls and then when I came back I was really sick and had to go to hospital and I think I was in there 6 months. (P4)*

Participant ten talked of how their parents went along with them and provided practical support for years. These were times when this participant stated that they refused to accept responsibility for their situation:

It took me from 1988 until about 1997 to get my act together and it was from a really hard but fair mum and dad and really hard old fashioned psychiatrist. We'd have to drive three hours to get there and he'd say 'you smell like grog, get out' and I drove home 3 hours. (P10)

Participants described how families often assumed a *caretaking role* and provided practical support when illness prevented them from meeting their own needs or carrying out their responsibilities.

Throughout my whole life I have had very supportive parents. They have loved me; they have supported me emotionally in a practical way. […] I lived with them for a while after I left home I moved back in they helped me raise my son until he was 3 years old and then my mother died, so, my son went to live with his father then, but just that sort of practical support of raising my son and just being around and knowing that I was loved. (P6)

My husband was very supportive too and I'd be crying when he'd walk in from work and I'd say I can't do any more, it was just too overwhelming to do one thing and he'd round the kids up and they'd all clean up and he'd tell me go and have a shower, that was his way of helping me; go and have a shower, and I'd have time out and I'd come out of the shower and he'd be cleaning up and cooking dinner but it's very important you have family support. (P4)

My sisters looked after the kids and I was in hospital for two months. (P5)

I've been married for 30 years. [Wife named] has been there for the ups and downs. (P1)

Strategies my wife has taught me [...] it's the basics that get you back on track, sleep, good food, bath every night, routine, medications. (P10)

I'm very lucky because I have supportive friends and family around me without which I wouldn't have come close to recovering. (P8)

My parents visited me every single day while I was in hospital and also my husband came every day too. (P5)

Brown and Kandirikirira (2008) conducted a narrative investigation of mental health recovery for 52 people who self-identified as having had an episode of mental illness which included but was not specific to schizophrenia. Participants within that study linked their families with providing sustenance, retreat, protection, care, sympathy,

understanding and help during difficulties; however the study also identified problems associated with family, such as being treated as a dependent and pressure from family expectations.

Participants described family as becoming comfortable with them being in an illness role and talked of how this could lead to family members being obstructive to the person's efforts to move out of the illness role. Challenges from family were described when some participants changed their role from the person with a mental illness being *cared for* to the person who assumed responsibility and took risks to achieve a better quality of life.

> *It is very popular to have a cross to bear and some mothers promote that in people. Families can work against people being independent and take responsibility. By protecting them, you, which they need for a certain time, end up disabling them. Dignity of risk comes into resilience. When someone wants to make an adventure into the outside world someone will say "it's a risk we don't want you to do that" but having a go; to keep having a go and to get that education across to them. (P1)*

> *He [husband] didn't want me on medication [...] sometimes I'd be well [...] I started thinking that he wanted me to be crazy so he could have another life out and I could sit at home and do all the housework. When the kids were little he took them with him [...] it was bad. (P5)*

For participants who had dependent children, there was a bittersweet quality to the experience. For some, being ill impacted upon the ability to parent:

> *When we separated the eldest one went with him, which upset me greatly and the youngest stayed with me. But then I wasn't very supportive of her and I used to sit out on the timber deck and chain smoke and she was an adolescent then and she used to sit in here watching TV. She was very upset about it and she had a big cry about it and she decided to go and join them and live with her father and sister. I got really, really upset because of my kids. (P5)*

> *I had a baby, although I wasn't able to raise him myself, his father raised him. (P6)*

Some strove to overcome problems because they wanted to do it for their children:

> *I wanted to do it for my kids I wanted to get them a stable life for them. (P4)*

> *I've got two beautiful little daughters, they say to [wife], mum because I code named the illness for the kids, so we call it Milko and the kids go mum, Milko's back and then they know it's not too late, it's never too late, dad's got to laugh, get some feed into him and shut up and go to sleep. (P10)*

Participants within this study described how seeing self as a victim of schizophrenia was a dangerous perspective to have because it led to staying trapped in the illness role. Family had a role in bringing insight to participants sitting in the role of being a victim of the illness:

> *My brother spent three months talking to me about being a victim. He banged his fists, he just didn't talk, he made his point really solidly. (P1)*

> *My wife took me to the Paralympics in 2000 and she said 'look at them [name], what are you worried about really, you've got all your arms and legs? Look at these guys and what we were watching at the time she said this was a blind long jumper with a guy down the front is yelling out left, right, left, left, right and he does this long jump and he would have jumped 7 metres and you can't measure the difference in illness, it's totally different but to see that strength. (P10)*

Family also had a role in reawakening hope:

> *I see the most important thing as family background. I have been to gaol and there was a time when the only thing that really inspired me was being able to hear a Pee Wee calling outside the cells of the gaol. Dad and I used to be in the yard together and he'd look for the grubs and feed the Pee Wees. That then reawakened hope at a dark time. I can recover and I can beat this problem. How important having a father and mother that you could say loved you. I am who I am and that is another thing that I found, finding who I am is important. The peewee story allowed me to reconnect with the child who was loved and the child who was nurtured. People traumatised by family and friends are not as strong and not as able to cope. Maybe not traumatised, maybe just neglected. (P1)*

In contrast, the removal of practical family support created serious challenges, such as homelessness:

My stepfather asked me to leave so that's when my homelessness started so there is a bit of tension if we discuss about the past but it's probably best we steer clear of it because it's not necessary, we just get angry. (P9)

I have a stepfather and he's a great bloke, he's really helped me out. My own father was a very violent man. I spent most of my younger days being threatened and being beaten every chance that he had. He refused to understand that I was ill. (P13)

I think when I am sick my family don't want to be around as much as when I am well. They cannot handle it. That mightn't be fair on them but I have found it to be that way. (P2)

Dramatic revision of family relationships may be a necessary first step towards taking responsibility, taking control and taking the pressure off:

After I decided to separate, I asked him to leave, I remember going to the movies by myself for the first time and during intermission, I went out to have a couple of cigarettes and I remember sitting on the steps having the second cigarette and I could feel a great weight had lifted off my shoulders. That was a terrible time, that marriage. (P5)

As participants talked about their sense of starting to gain control, they described the need to actively maintain the support and goodwill of family by not being passive recipients of care but also by *'caring for carers'* and giving care back. By doing this, participants felt that they were maintaining a balanced relationship.

It's very selfish this disease. I look after my carers and I make sure they are cared for. I spoil my carers. (P10)

Despite there being some challenges, particularly when the person was in the early days of their illness, the majority of participants described the role of family as very much supportive in nature. Family became increasingly more valued as the person gained greater insight into their illness.

A search of existing literature to further explore the family role of people with schizophrenia from the perspective of how they value their families and for what they contribute to family life revealed a paucity of information. The orientation of existing

literature is very much towards educating 'suffering' families who are feeling terrible loss and grief and experiencing burden, rather than exploring the positive role played within the family dynamic by people who experience schizophrenia (Loukissa 1995; Lowyck et al. 2004; Magliano et al. 2000). Given the historical attitude of blaming the family for the presence of the illness (Corrigan, Watson & Miller 2006), taking the opposite view of the positive side of the experience of having a family member with schizophrenia would be an important area for future research, if only to provide some balance to an old and worn out argument.

Walton (2000) explored the relational aspects of living with schizophrenia and identified that people living with schizophrenia worked hard at maintaining helpful relationships, particularly with people who understood them and showed concern for them and they avoided relationships with people who did not understand or who were unkind.

Analysis and interpretation of the full range of descriptions captured within the element of family resulted in the following statement; family both supported and challenged me, however, it's important to manage difficult relationships, to trust others and care for the people who care.

Work

Work was another element identified in the analysis. The interpretation of participant descriptions was that work is something that needs to be newly created after the significant illness experience of schizophrenia. None of the participants interviewed was in their pre-illness work. They had to reinvent their working life and the extent to which they were able to do this was very much dependent upon getting the side effects

of medication under control, finding a workplace that didn't contain stigmatisation and create the potential for being a victim and furthermore, one that had the capacity to address the challenges associated with working with people living with a mental illness. Once work was in place, participants indicated that considerable capacity to deal with pressure and to cope with stress while earning low wages was necessary to maintain employment. Once these challenges had been overcome, it was possible to gain a sense of competence at work and to take advantage of opportunities for advancement. Whilst this was seen as bringing more stress, it was identified as 'different stress' because it was part of growing one's work life in a desired direction. Contributing to the capacity to cope and to grow was having professional help to call upon when necessary, having medication as a supportive element in life, being within a supportive family system and also to living a healthy lifestyle characterised by good diet and sufficient sleep. The journey of establishing a new work identity was about resilience:

> *Find work, a hobby or exercise you have to try and try and try. This is about resilience, to being able to try again that you have failed. To see it as failure is wrong. You need to have another go and stigma goes against that when you fail that everybody is judging you because of your mental illness [it's] disability plus stigma. (P1)*

Work plays a very important role in providing an identity and defining an individual (Lehman et al. 2002; Seeman 2009; Twamley, Jeste & Lehman 2003).

> *I think [...] a lot of people get their identity from their work, from their professional role but for a lot of people with schizophrenia I imagine they are on the disability support pension and they don't get much self-confidence and self-esteem from their work role because they haven't had one for quite a while [...] my work, my four community organisations and my strong world view make up my resilience. (P9)*

Studies conducted within the United Kingdom (Crowther et al. 2001) identified that despite high levels of unemployment, people with serious mental illness want to work.

It was very important that I found out I could still work. That was really important to me. (P5)

I was at a group and one of them had work, he went along to the CES and I thought great, I'll have a go at that. (P12)

Dunn, Wewiorski and Rogers (2008) investigated the meaning of employment for people in recovery from serious mental illness and identified that work fosters self-esteem, provides financial benefits and provides coping strategies for illness symptoms.

It was really good; it meant I bought my own home in the end. (P6)

We've still got a mortgage, I still have to work. (P4)

With the anxiety I sit in the lounge and relax and do slow breathing and I find sometimes I'm there for half an hour, sometimes an hour, the time just goes so much better and I just feel better, I can face having to go to work that night. (P6)

Marwaha and Johnson (2005) thematically analysed the views and experiences of employment for fifteen people with psychosis in the United Kingdom. Their findings indicated that people didn't disclose to potential employers that they live with a mental illness because they feared being discriminated against. Within this study, participants didn't discuss whether they had or hadn't disclosed their health condition but they did recognise that they were working differently to others:

Your disability may not be the reason that you lost your job, it may be that your work mates found you different and victimised you. (P13)

Not able to work now, no, I was working in a public service for a total of 19 years, I had two periods I had the baby in between and I had a lot of support from my work colleagues, and I think they got support from counselling on how to deal with people like me in the workforce because I was disabled I was a little bit destructive so as far I know they just did coaching to look after me, well not to look after me, but to get along with me, so it was really good. (P6)

People don't want their identity defined by an illness such as schizophrenia, as occurs for example, when the term '*schizophrenic'* is used to categorise them (Seeman 2009).

Link et al (2004) reviewed 123 articles assessing mental illness stigma published between 1995 and 2003 to conceptualise the stigma process. Within this, they found that the identification of human differences results in emotional reactions by a person who then becomes the stigmatiser. The person being stigmatised experiences status loss and this is then followed by discrimination.

> *I went to that place where they try to find people with disabilities a job, CSR or something and then I went for a few job interviews and no luck anywhere because there were hundreds of applicants and they told me you're competing with people who haven't got mental illness. (P5)*

Finding employment while living with mental illness requires striving which is well explained by the try, try and try again attitude described by participant one earlier. Sometimes the challenge was seemingly too great for an individual to overcome.

> *I try my best to find employment but most of the time my power to succeed isn't there. (P14)*

> *I suppose to me resilience was I went back 6 years ago when it was like I had lost my whole cognitive ability to work and understand. (P11)*

> *So I went on that path lasting 6 months in the job and I'd noticed I was going downhill and I was a good worker and I did good work but then I'd get to that peak point and I'd know I need to leave on a good note and they'd say "what happened" and so I'd always resign, I wouldn't get the sack. I'd disappear and quite often I was back in hospital. (P10)*

Other findings within the Marwaha and Johnson (2005) study on employment experiences was that participants held doubts about their ability to work in relation to illness symptoms, medication side effects and the potential for further damage to their health.

> *I was so gutted with my health and lost my car and my job my apprenticeship. (P10)*

> *I can't work now because I just find it very stressful because with jobs you have to talk to people day after day and be with people I can't do that. I'm retired because I can't cope with work now. (P6).*

I wasn't able to maintain the job, I think that was mainly through the medication also at the time I found it hard to think properly and stay awake during the day. (P11)

I find if I do too many hours at work, I can't cope with it' [...] it's just too much pressure [...] I get too overtired. (P4)

Barriers to employment for people with schizophrenia were investigated within the large (1,438 participants) CATIE study (Clinical Antipsychotic Trials of Intervention Effectiveness) (Rosenheck et al. 2006) conducted in North America which primarily looked at the relationship between antipsychotic use and employment rates. The study did not explore the challenge and potential barrier of medication side effects which have been described by participants in this study, however within the CATIE study, disability payments were found to be a disincentive to achieving competitive employment.

I was never afraid to work but I wouldn't accept second best, I wouldn't, it might be my arrogance but I wouldn't accept a sheltered workshop. I worked, I cleaned the showers and the toilets at the backpackers in return for sleeping in a sleeping bag with some floor space but he taught me the backpacker's trade and I ended up managing it. (P10)

A friend of my wife's told me about a supportive employment agency. I decided to give that a go rather than giving in to going on the disability pension. I still found it hard to keep going because the job I was doing was only paying $6 an hour through the disability support network anyway. I kept going with it just because I couldn't see that there was anything else to do. (P11)

Crowther et al (2001) conducted a systematic review of evidence obtained from eleven trials including 1,204 participants on the most effective way to help people affected by serious mental illness to obtain employment. Supported employment was defined as maintaining work within a competitive job market while simultaneously being supported to be effective within that role. Prevocational training included sheltered workshops, work crews and skills training within rehabilitation schemes. Crowther et al (2001) found that supported employment was more effective than prevocational training. Within this current study, participant descriptions how whenever the

opportunity to work presented itself, be it, supported or prevocational, it was treated as a

stepping stone to better opportunities and more responsibility in the future:

> *I proved myself in the job which was basically doing kitchen hand work [...] on this supported wage [....] the new owner saw my work and offered me a job on full award wages and that gave me the confidence to start again to look for other employment. (P12)*

> *I got a job with homecare just cleaning people's houses, then I got a job as a mentor, then a youth worker then this job as a support worker. Even now I think I'm probably only 70-80% of my full potential. (P11)*

The ability to recognise an opportunity and go with it is described by Masten (2001) as

a trait of resilience. The ability to work is something that is interrupted and changed by

living with a mental illness (Marwaha & Johnson 2005). Regaining work is important

for the self-esteem and economic support (Marwaha & Johnson 2005). The symptoms

of mental illness, the side effects of medication, the expectations of the workplace and

the attitudes of others must be coped with in order to be able to build a new supportive

working life.

Stimulation

Another element titled stimulation was achieved from having meaningful pursuits. Rich

descriptions were provided by participants for the reasons why stimulation is important

and these have been synthesised into the following paragraph which was created by

uniting participant voices to tell the story:

> *I was backed into a corner, with very few options .... I needed an outlet for frustration ... caused by long, slow medicated days with nothing to do ... I have to stimulate myself otherwise I end up going crazy ... find a hobby work exercise and you have to try, try and try ... for some reason I stuck with it ... when it starts off I might be a be awkward and that sort of thing but with a bit of practice you get better at it and it doesn't seem to take long and you can be very good at something pretty quick. It's a matter of picking things up and having a go and ... you have to be encouraged to create a surrounding for yourself so you are stimulated and continuously*

motivated. Stimulation and motivation are very important. Anything to keep the mind stimulated. That I found has been my greatest challenge….

The following quotes describe ways in which participants fulfilled this desire for stimulation. Again, these descriptions have been synthesised from many participants:

I've learned to play the violin and the piano … I work on the computer, I read constantly, whether it's music comics, I collect comics I'm into all sorts of things. I go out a lot fishing, I have a motor bike I'm building.

Pursuing stimulating activities also involves cost and for participants who are not earning an income from working, it was challenging but thought of as necessary to find the money to support activities:

I mix music, I'm teaching myself musical engineering. I gamble, I go to the club, I've made a considerable amount of money through gambling and poker machines and I've invested in stereo systems and computer equipment and through that entertainment I mix sound tracks and sooner or later I intend to get into producing music myself, I've gained quite an understanding.

As well as achieving stimulation by keeping the mind active, participants also engaged in calming and pleasurable pursuits:

The garden was a big thing for me, you mightn't think it was very important but I love, I really love it ... a little bit of meditation ... I also find meditation contributes to my resilience. I try to meditate every day for an hour. (P5)

More importantly, these activities have resulted in significant outcomes for participants, including leading to new work roles:

I'm always an ideas man and I thought well how I could turn this into a job and it took me a while and it felt like I was sitting there in depression for a while so I got the women in the street up and going and started pram groups and then I became a volunteer one day a week in the hospital and we started a real pram group and I suppose I was noticed because […] I've never hidden that I walk with a mental illness. (P10)

Participant four was 'noticed' within the health service because of their volunteering. They then moved into a paid consumer advocate role and then branched out into

speaking at public forums about their illness experiences and the pathway to recovering. Other participants also described the creation of job roles out of participating in activities:

> What I'm proudest of is my four community organisations that I assist to run. [Within one of them] we made our first movie last year we're making one movie a year. Those four organisations are my pride and joy and I'm very proud of them and I work hard at them and I guess compared to a lot of other people I do a lot more community work in a voluntary capacity. (P4)

> I seized on writing as something to fill the time in the long slow medicated days with nothing to do so I started writing short stories at that point and I didn't think they were all that good and looking back at them they are really terrible but I thought they were great at the time. For some reason I stuck with it which is really out of character for me to stick with something and put some effort in and eventually the work showed enough improvement that when I came to my senses and was inclined to do something sensible with my life the work justified the pursuit. And eventually I was able to get published. (P8)

That participant's first piece of writing achieved seven separate literary awards and led to them having another five pieces of work some of which have also been shortlisted for awards. This participant gave permission for their achievements to be highlighted within this work.

Another important aspect of engaging in stimulating activities was because they give to others and also give back to society, thus increasing self-esteem and contributing to the development of a valued role within society:

> What is of most significance is your contribution to your family or your community or your society or your civilisation of whatever contribution you can make. My catch phrase is 'NO INNOCENT BYSTANDERS'. With telecommunications like we have today you cannot be unaware of the world's problems and you are as a citizen especially in Australia, you have a responsibility to be involved and help solve these problems so you can't deny you don't know. That's part of my world view "NO INNOCENT BYSTANDERS" [loudly emphasised by participant] ... everyone's involved, they're all our problems and we've got to work and this is my resilience. (P9)

What was noticeable about participant's descriptions was that the activities involved were generated by the participants themselves, according to their own desires and interests, rather than being formally structured activities as part of a service driven rehabilitation program. They developed out of participant's individual life contexts. An English study of the rehabilitation group experiences of twenty four people who live with psychosis highlighted experiences that were not conducive to gaining benefit (Cook & Chambers 2009). For example, group leaders behaved uncaringly and adopted disrespectful attitudes, and activities were not generated according to the actual needs and desires of participants (Cook & Chambers 2009).

Within this current study, some activities were solitary pursuits and some were group activities. Descriptions indicated that it was dependent upon the participant's preferences around experiencing social stress. Activities that involved other people with schizophrenia were favoured by some and avoided by others:

> *I go to an art group with other people with schizophrenia so I quite like that but I can't go regularly as it just too much for me but I can go occasionally and I find it very good. I find I relate well to people with schizophrenia, I like to relate to people with schizophrenia. (P6)*

> *I sometimes think mentally ill sometimes mix too much with mentally ill and it becomes a major issue in their life. (P2)*

Mixing socially with other people is understood to be difficult for people with schizophrenia because some of the symptoms lead to social withdrawal (World Health Organisation 1993). This withdrawal can be because of difficulties in establishing and maintaining relationships with others, which may be related to feeling insecure, frightened, or paranoid around others (Erdner et al. 2002; Hvalsoe & Josephsson 2003; Nystrom, Dahlberg & Segesten 2002). However, Davidson and Strauss (1992) analysed the narratives of 66 people aged between 20 and 55 years who were living with

schizophrenia and identified that participating in activities with other people was a way of creating meaningful relationships.

Tooth et al (2003) interviewed fifty seven Australian people living with schizophrenia to identify important factors for recovery. Sixty four per cent agreed that finding their own way to manage the illness was important. For the participants within this current study who were not working, having meaningful interests was seen as very important for quality of life and maintaining wellness. Having a sense of meaning and purpose in life has been identified in many studies as important by consumers for achieving and maintaining wellness (Andresen, Oades & Caputi 2003; Cook et al. 2012; Glover 2005; Ridgeway 2001; Tooth et al. 2003).

Stress

Stress was described by participants as a major challenge in their daily experience of living with schizophrenia. Many different approaches to stress were described from avoiding it through to dealing with it as an expected part of normal daily living.

> *You can worry yourself and you can trigger it yourself with or without and so you can talk yourself into very bad situations like if I'm very tired, and I haven't eaten properly, and I'll just bugger off to the pub and I might have six drinks or so and stay up another night and then let everything in your door, everything, let it all in and Jesus you can weigh yourself down. (P10)*

For a person living with schizophrenia, there is a vulnerability to stress. A causal relationship between stress, vulnerability and schizophrenia was established in the 1970s (Zubin & Spring 1977) and remains valid (Gispen-de Wied & Jansen 2002; Keshavan et al. 2008b; Masten et al. 1999; Resch 2002; Schore 2003; Waddington & Scully 2002).

> *Stress is my mental illness and [you've] got to be more sensitive to addressing your stress if you have a mental illness and react appropriately*

but that obviously doesn't mean you put yourself in moth balls or cocoon yourself. (P9)

Genetic vulnerability to schizophrenia provides an individual with a threshold ability to cope with stressful events and encountering stress in excess of this tolerance leads to decompensation of mental state to the point where clinically diagnosable symptoms such as an episode of psychosis emerge (Garmezy 1971; 1993; Gispen-de Wied & Jansen 2002; Keshavan et al. 2008b; Tienari et al. 2002; Zubin & Spring 1977).

I can tell when I'm having a bad day and when things are too overwhelming, I know that it's a symptom. (P4)

I just couldn't cope with stress, when you are unwell you automatically lose all coping skills. […] When I was working, less stressful work, I just couldn't cope with stress. (P2)

I can't work as a nurse any more. I don't want to work as a nurse anymore anyway, it's too stressful and it will make me unwell. Keeping stress out of my life, having things I love to do. (P5)

I used to do TAFE course and work at [name] as a volunteer and do [charity] and I used to check on things that caused me stress and I used to get ill during exams. (P2)

I really am managing better in the last 2-3 years where I am handling stress better. I don't know what it is but there is something causing it. I …. Think that before I had a more low level tolerance of stress. Whether it is maturity I don't know. (P2)

Furthermore, chronic stress has been shown to damage the plasticity of central nervous system responses resulting in stress-induced inflammation in schizophrenia which erodes the ability to mount a resilient response to a challenge (Gottesman & Hanson 2005; Müller & Schwarz 2009).

Not able to work now, no, I was working in a public service for a total of 19 years. […] I can't work now because I just find it very stressful. (P6)

Despite often negative consequences of stress, all stress cannot be avoided and moderate amounts of stress are said to be protective (Seery 2011). Successfully

engaging with low levels of risk creates a *steeling effect* which according to Rutter (1985; 1987) enhances coping and builds protection.

> *People in the church that were upsetting me, I suppose that's what it was, it was absolutely, terribly stressful, I thought I'd end up in the inpatient unit I was so stressed. It was people that were causing the distress and I mean my faith has grown as a result of that experience [...]. I mean your faith is in God. If it's a mature faith its God who is the one you're serving and the one you're loving, more so than people in the church. It was a growthful experience. (P3)*

The Challenge Model which was explicated in chapter two, section two, is based on the theory that low levels of risk stimulate the person's use of protective resources, and if the experience of risk is followed by successful coping, it strengthens and stimulates the protective resources (Hollister-Wagner, Foshee & Jackson 2001). Within resilience theory, Richardson (Richardson 2002; Richardson et al. 1990) describes a 'simple' linear resilience process for encountering stress during which a person experiences stressful or adverse life events which disrupt their mind, body and spirit. While in the disrupted state, the person acts to invoke protective resources to ameliorate the threat posed by the stress or adversity. The person then moves from the disrupted state into a reintegrated state of physical, mental and spiritual homeostasis.

> *I told someone recently about people throwing boulders in your path. It's ok to stop and take a breath but you must keep going. But know this; you will get through that and see the light you'll feel a hundred foot tall, but look in the distance there'll be another mountain. So once you have gone through a few of them, and it's nothing to do with schizophrenia its life what's happening to you, once you have gone through a few of them for that brief moment when you have just broken through the last one, you go ... bring it on I'm ready. And you walk through that plateau like a rainforest and you know that mountain's coming and I don't stop, I face it now and I lock horns with people along the way. And it's GET OUT OF MY WAY. But the gift of getting through the mountain is not telling other people to get out of the way, its allowing them to take a bit of weight for you. (P10)*

Participant ten's description is characteristic of Richardson's (2002) identification of resilience which requires a person to gather new protective resources and coping skills

along the way while dealing successfully with stress or adversity. Participant ten recognised that by pushing on up the mountain, they learned how to climb it, and therefore they could climb other mountains. Participant ten also recognised that they needed to allow others to share some of the weight of the journey. Other participants within this study spoke of the need to maintain supportive family relationships, to maintain manageable social relationships and to get adequate sleep as strategies for sharing the weight and coping with their own personal stress mountains.

> *I'm happy to do what I do and then stressful things come up and [wife] gets involved. (P11)*

> *I've been told by the doctors that for me to remain well the two main things to worry about are sleep deprivation and stress. Basically I try to get 8 or 9 hours sleep a night. (P11)*

> *My faith was challenged I suppose you could say my faith deserted me perhaps and I was stressed and I couldn't sleep and I was in a pretty bad way. I called in the local mental health team and they gave me some sleeping tablets and I got a bit of sleep and well I just kept going. Another thing that has probably helped me is journaling, I journalled all through [wife's] illness and wrote things down and I suppose, I try to get a better understanding, to reflect. (P3)*

In Masten's (2001) concept of resilience the greater the stress and strain, the higher number of protective resources required to buffer against the associated risks turning into a state of reality. Participants identified that not every stressful situation was to do with their illness and that it was a relief to realise that "it's just normal life stress that's happening". One participant developed a coffee tin full of objects of which each had a symbolic meaning for the fight against stress:

> *So I've got these symbols of my own in a coffee tin; I've got a band aid [wound plaster] that says it's OK to be hurt but it can be fixed, a little piece of paper that says 'go for a walk'; a wishbone of a chicken; it's okay to have dreams and goals and wishes that are achievable. I have a peg in there; it's OK to be a stay at home dad. There's a shell in there; it's OK to hibernate, every shell has an opening, and we'd surely perish if we don't come back out. A piece of cotton to wrap around the finger tight; everyone*

hangs on by a string the important thing is to get a good grip and hang on. (P10)

Coping with the normal stresses of life is a component of the definition for a state of *mental health* which was created by the World Health Organisation (2004). Coming to view change or stress as a challenge or opportunity is a characteristic of personal hardiness, or resilience according to Kobasa (1979).

Social ties

Within this study, descriptions of the social element of the experience of schizophrenia were powerful and were considered as being both supportive and challenging. Friendships were valued supports however they were also considered challenging when symptoms of schizophrenia became evident. Stigma was implicated within this challenge and lead to the loss of friendships. Some friends issued challenges to think differently, to realise something or change and to grow, however the nature of the challenge was not one that overtly threatened the friendship if the challenge was not immediately acted upon, therefore it was a challenge within a supportive relationship. The following excerpt describes both experiences; challenging and supportive friendships:

> *But there was a fellow and he was a good friend of mine and I played junior league with me and he went through horrendous sexual and physical abuse, and after a few years in my treatment I was lying flat on my back on this lounge in my mum and dad's farm house and I did that for about two years, I ate dried spaghetti sticks, I was beyond suicide, I was dead, I didn't care if I killed myself. I was starting to break down I was a mess, so wounded and this fellow did some quite time in juvenile gaol, some time in Goulburn jail. He's got a wife, two kids, two houses, runs a business and what he said was there's no rock bottom, it's a bottomless pit. Depends on how much strength you've got to pull yourself out of the hole. There's always a hand to grab, make sure it's the right one. To me they're clichés but and you don't hear them when they're said, you hear them later. And you go what's he doing, look at him; look at what he's been though. (P10)*

The particular friend of the participant had challenged them to find the strength to accept a hand up out of their predicament. On the other hand, another friend couldn't accept that the person was unwell, wanted to remove them from an involuntary hospital admission and take them back to work; back to a *normal* life:

> *I remember this mate of mine, a footballer, he was a tough little bugger, came to visit me, and said you can't be in here, I can't believe they've got you in here, there's nothing wrong with you, [...] and they gave me an hour leave with him and he threw me in the car and started driving back to [place], and I was actually the one that said, (mind you I was non' compliant every time, the police escort and the whole bit), and I said "what are you doing mate, take me back, you can't do this", because he was actually heightening my paranoia, and so as much as you kick and scream in that situation you actually know you're not well. You're not going to own schizophrenia or depression or bipolar or whatever they want to throw at you! You're not going to own that you can't get out that day, but when I was put in that position with this guy, this friend of mine [who] was going to throw me in his car and drive me back to my job as such, I was like what are you doing? Good mates; five or six good mates, there's no doubt they stir me up some of them walked away and key ones came back. (P10)*

Boydell, Gladstone and Crawford (2002) interviewed twenty one people living with psychiatric disabilities in Canada to identify the meaning and importance of friendship. They identified that friendships with peers encompassed an enhanced level of understanding, support and acceptance and also alleviated alienation and loneliness.

> *There's a man in my life who's probably 20 years older, I call him the guardian angel and he has been a guiding influence in my life and without that influence I wouldn't be well today I don't think. (P1)*

In contrast to professional relationships, peer relationships were reciprocal for both giving and receiving support.

> *I have a male friend and we contact each other nearly daily and I visit him and he suffers badly from schizophrenia and that is another thing, I have his support which really does help. Even though his illness is less stable than mine but we really do support each other. My social activity is his friendship. (P2)*

The Boydell, Gladstone and Crawford (2002) study also found that supportive friendships enhance the ability to cope with life stressors and vulnerabilities and these run parallel to the definitions of resilience within the extended literature (Becvar 2007; Masten 2001; Richardson 2002; Tusaie & Dyer 2004). Having strong social connections is known to be the most robust environmental factor impacting upon a person's resilience but social rejection is said to erode resilience (Hanson & Gottesman 2012; Jurgens & Johnson 2012; Slavich et al. 2010a; Slavich et al. 2010b). Social rejection and the loss of friendships is associated with a lack of acceptance of psychiatric disabilities, outright rejection and stigma (Boydell, Gladstone & Crawford 2002).

In a review of the literature on social ties and mental health, Kawachi and Berkman (2001) found that functional support buffers the effects of stress by enhancing a person's coping abilities. Support groups of the type that participants described attending offered functional support; that is they enhanced functioning in some way:

> *There have been support groups over the years that have helped me. I think it didn't help a lot of the other guys, some of them are still there but they aren't willing to go to different people to get help. You just try things. I guess that was it, I wanted to be a normal person so I was willing to try things. (P12)*

> *It was a growthful experience and I was in Grow. Have you heard of Grow? I was in Grow for 8 years and that was where I learned about love, this affective and effective love. I learned about love in Grow and we say in Grow growth is painful but permanently rewarding and this was painful but permanently rewarding, it was growth. (P3)*

In a broader social sense, involvement in social structures such as participation in community organisations, and involvement in social networks have been found to be important for gaining guidance about health relevant behaviour, social integration which

brings a sense of purpose, belonging and security, increased motivation for self-care and also buffering of the stress response (Cohen & Wills 1985).

> *What I'm proudest of is my four community organisations that I assist to run and I'll tell you about those and these would be resilience or I believe it's important that you be a community player. (P9)*

However, the previously mentioned Boydell, Gladstone and Crawford (2002) study identified that there may be a limited range of experiences to be had within special purpose groups, such as an illness specific support group. This was highlighted by participant six who stated that when mentally ill mix with mentally ill it all becomes about the illness, which is not enjoyable or desirable. Groups were said to be enjoyable but limited social exposure was thought to be necessary:

> *About once a month I go to an art group with other people with schizophrenia so I quite like that but I can't go regularly as it just too much for me but I can go occasionally and I find it very good. I find I relate well to people with schizophrenia, I like to relate to people with schizophrenia. (P6)*

The need to restrict socialising in order to maintain wellness was realised and accepted:

> *So that's it I am just functioning pretty highly, my psychiatrist said I function highly. I am highly functional, so as long as I live a quiet life now, keep to myself a lot of the time, I have a few friends, don't join any major social groups, no clubs or anything like that, nothing like that, just live a quiet life, not go many places, not do much, then I am fairly stable. (P6)*

Feeling uncomfortable in the company of others was identified as a theme within the experience of schizophrenia by Walton (2000), who identified the reasons as having difficulties in meeting new people, sustaining friendships and setting limits as well as physical feelings of being uncomfortable around others. Within Walton's research, feelings of stigma were linked with revealing the presence of schizophrenia when forming new friendships.

Stigma

Stigma, an element identified in this research, is a burden borne by those diagnosed with schizophrenia (Ayuso-Mateos 2000; Begg et al. 2007; Corrigan, Roe & Tsang 2011; Knapp & Razzouk 2009; Walton 2000). It is a challenge to a person's humanity and is socially costly (Biernat & Dovidio 2000; Corrigan, Watson & Miller 2006). The diagnostic label of schizophrenia is made up of a set of truths that are value laden (Kapur 2011) and which are judged against a backdrop of normative socio-cultural perspectives (Robertson & Walter 2007). Against these norms, a person labelled with schizophrenia becomes discredited (Goffman 1968) and society no longer sees the person, only the mental illness (Vellenga & Christenson 1994). The previous self is lost and the person is propelled into a mentally sick role accompanied by stigma (Robertson & Walter 2007).

> *I had different ideas about what the illness meant before I had it myself. I would have crossed the street if someone told me a schizophrenic was walking on the other side of the street. (P8)*

> *There's a lot of abuse that comes with schizophrenia, a very great misunderstanding a lot of people's thought processes concerning themselves to us. That's the hardest part of schizophrenia because there's a lot of shame attached to it. The social stigma that's attached to it, people look at you and oh you're schizophrenic, you're a criminal, you're a freak, you're a danger. (P13)*

> *Stigma goes against that when you fail that everybody is judging you because of your mental illness. (P1)*

> *I felt if that was my label, I had to fit it; it was peculiar. When I first got told I was schizophrenic I thought there was set of norms I had to follow, but that didn't last long thankfully. I made it back when I should have. (P8)*

Link et al (2004) reviewed 123 articles measuring mental illness stigma and conceptualised the components of stigma as being labelling, stereotyping, cognitive separating, emotional reactions, status loss and discrimination. Whereas Thornicroft et

al (2008) considers that stigma can be understood as a combination of problems of knowledge (ignorance), attitudes (discrimination) and behaviour (prejudice). Corrigan, Kerr and Knudsen (2005) describe two elements of stigma; public stigma and self-stigma. Public stigma is the way in which the general public group together in their opinions to endorse stereotypes and to act against the stigmatised group who fit the stereotypes and self-stigma is the way in which people internalise the public stigma and then feel a loss of self-esteem and self-efficacy (Corrigan, Kerr & Knudsen 2005).

Dinos et al (2004) studied the effects of the experience of stigma for 46 people who live with mental illness in North London and identified that stigma was a pervasive concern to all participants. Receiving a mental illness diagnosis caused their participants to *feel* stigmatised, even in the absence of any actual discriminatory acts by others. When there was overt discrimination, the consequences were anger, embarrassment, fear, isolation and feelings of depression (Dinos et al. 2004). Addressing public stigma requires social marketing campaigns at the population level (Thornicroft et al. 2008) and is therefore a much larger issue than any individual who lives with a stigmatising mental illness can deal with, however, self-stigma can be influenced. Kingdon and Turkington (1991; 2000) found that changing the way of thinking about stigma, by coming to consider it as a normal event, had the effect of helping people accept their mental illness. This is described by the following participant when they changed their thinking around stigma:

> *Disability plus stigma .... ordinary resilience isn't enough, you need more, you need to be able to understand why people are discriminating against you and how it works. Try not to take umbrage. Having a graceful way of understanding that it is their ignorance that leads them to judge you that way and try not to be affected by it. I am who I am, finding who I am is important. (P13)*

Crabtree et al (2010) studied 73 people who attended mental illness support groups in the South West of England to establish whether association with other stigmatised people in a group setting would buffer people against the stigma associated with their illness. They found that peer support in a group increased social support and provided access to stress-buffering mechanisms and when these were learned and put into action, self-esteem increased as a result of feeling good about being able to cope with the stigmatising attitudes of others.

Lifestyle

Lifestyle emerged as an element in this research. The way in which a person lives their life, or their *lifestyle* is considered to be a matter of choice (Connolly & Kelly 2005), however, for people who live with schizophrenia, literature is replete with discussion on how factors related to the illness directly interfere with the ability to create a healthy lifestyle. Research has identified problems such as a lack of motivation, the interference of psychotic symptoms, lack of knowledge about physical health and the side effects of medication (Abed 2010) as issues that affect lifestyle. In contrast to the descriptions within this study, other studies on how people living with schizophrenia spend their time have found that their main activities consist of walking to the shop to buy snacks or cigarettes, drinking coffee, smoking and watching television (Bejerholm & Eklund 2004; Harvey et al. 2006; Levaux & Danion 2011; Minato & Zemke 2004; Weeder 1986).

However, within this current study, positive lifestyle activities were described by participants and included volunteering, craft courses, church, playing musical instruments, mixing music, meditation, fishing, building a motorbike, gardening, art, sewing and making movies.

Lack of motivation is a much discussed correlate of unhealthy lifestyle choices for people living with schizophrenia (Abed 2010; Choi & Medalia 2010; Connolly & Kelly 2005; Hasnain, Victor & Vieweg 2011) however many studies use laboratory type conditions to administer specially designed questionnaires or tests to 'measure' motivation. No studies could be found that evaluated participant's own descriptions of their lifestyles within their natural environments. Many of the interviews for this research were conducted in participant's own homes and therefore the evidence of their lifestyle activities were there to see; gardens, craft, art, musical instruments and equipment, model kits, bicycles in hallways. Furthermore, all of the lifestyle activities described by participants were of their own choosing, and were engaged in because they interested and rewarded the participants, not because they were administered for scientific purposes. Tests designed to measure motivation lack the stimulation of naturally selected activities (Abed 2010). Motivation was not mentioned by participants within this study as being a challenge for them that couldn't be overcome. On the contrary, the need to stay motivated was recognised:

> *You have to be encouraged to create a surrounding for yourself so you are stimulated and continuously motivated, stimulation and motivation are very important. (P13)*

As such, participants recognised the need to make lifestyle choices that countered the challenges of schizophrenia and described this as a process which took many years:

> *I think I was going downhill there for a long time. But what I think that I changed my ideas of what it was, I quit smoking and that made a big difference to my life. I fixed myself up. I had this thing going on where I was accepting that was the way to go with schizophrenia, and I thought, it was something my mother said, "all you guys always smoke" and I thought Oh I didn't want to be like that and so I made a decision to quit smoking for a while. It took a while to get there and I think felt a lot of power when I quit smoking, more in control of my life and that sort of thing, it was a big change but I felt a greater control of my life. Then I managed to quit other things, like drinking which was a big part of schizophrenia, people I know are into drugs and stuff. The whole lot I've changed to a healthy*

lifestyle, I thought that I'd make improvements to be the best that I can. It was just a bit like going through resilience, you'd start something and then you'd have to go to the next thing and somebody would say an idea and I'd think that's interesting and that would keep me going. That's the way I look at it. (P12)

Living a healthy lifestyle was seen as important for maintaining resilience and was described as being achievable through "eating well, sleeping well and behaving well" Ways that participants indicated they could do this included; drinking water, eating fresh food including lots of fruit, not smoking, not drinking alcohol, meditating and having a faith. Continuously working on the physical and emotional state was described as necessary for living a healthy lifestyle, which in turn contributed to maintaining resilience and a stable state of physical and mental health.

The last ten years it's been changing my lifestyle to a healthy lifestyle which is definitely the way to go. I read, I exercise, I go out kayaking, I do tai-chi, a little bit of meditation which I've found a great help to me more recently. Cooking was one thing that helped me with my resilience. (P12)

Physical health

Although physical health is recognised as a component of lifestyle, it has been identified as a separate element within this study through the inclusion of health factors such as diabetes and hormone fluctuations in participant descriptions. Since about 1988, metabolic disorders have been identified as major risk factors for people diagnosed with schizophrenia who are taking the newer anti-psychotic medications (De Hert et al. 2006; McEvoy et al. 2005; Meyer & Stahl 2009; Reynolds 2006; Thakore 2005).

So I went on [medication] for 6 years and it wasn't very good and I nearly ended up with diabetes. I got very fat, my blood sugar started to rise and my psychiatrist and doctor became alarmed, so after 6 years I have gone back to [medication]. (P6)

I've put on weight, 5mgs more [medication] has given me a bit of tummy weight and since I've put on all this chop it's been very hard to motivate myself to walk. (P14)

Metabolic syndrome is caused when physical irregularities lead to insulin resistance which then increases the risk for developing Type 2 Diabetes and cardiovascular disease (Meyer & Stahl 2009).   Metabolic risk factors are smoking, high cholesterol, hypertension, physical inactivity and obesity and anti-psychotic medication (McEvoy et al. 2005; Nasrallah 2008).   Hypertension and obesity risks are moderated by exercise, risks from smoking are moderated by cessation and high cholesterol is moderated by diet and medication risk is moderated to changing medications (McEvoy et al. 2005; McLeod, Jaques & Deane 2009; Meyer & Stahl 2009; Nasrallah 2008; Vancampfort et al. 2011). As such diet, exercise and smoking are important issues when living with schizophrenia.

Vancampfort et al (2011) studied the exercise capability of 60 Belgian people living with schizophrenia and found that they associated exercise with discomfort and pain, which lead to them having a reduced capacity for exercise and then to leading a sedentary and unhealthy lifestyle. Within this study, the physical nature of schizophrenia was described as:

> *People that haven't been there that don't understand, it's so physical, it's the physical energy, your heart aches, you feel hungry, you ache all over, you say goodbye to your mind. (P10)*

However, within Australia, McLeod, Jacques and Deane found the opposite with regard to exercise levels of people with schizophrenia in their study of 125 people.   They identified equal levels of physical activity with the general population, however 70 per cent of people in their study were obese and this was attributed not to lack of physical exercise but rather the effects of diet and medication. Participants within this study also mentioned the appetite stimulating effects of their medication (Hasnain, Victor & Vieweg 2011).

[Because of the medications] I could eat, eat, eat. I keep busy all day. (P5)

Being obese was described as *unhealthy* and *not OK*. One participant pointed out that it was not good to accept or normalise a state of being overweight.

> *I don't believe in making fat people feel comfortable about being fat, there's no doubt about it, it's unhealthy to be overweight. 'I don't cook at home, I eat out every night. My job allows me to do that but it's a problem. [...] When I look in the mirror, drying myself after having a shower, I do not like it. If weight loss was easy, then no-one would be overweight would they? I have done it before, I haven't been this heavy, I'm the heaviest I have ever been, but I have been quite heavy and lost quite a bit of weight but for me to get to my goal weight I would have to lose a third of my body weight which is quite a lot. That eats away at your self-esteem and your resilience. (P9)*

Physical activity was used as a doorway to change and one participant described experiencing an awakening of the mind. This 'enlightenment' was accompanied by the urge to get on the kitchen floor and do one push up and one sit up, followed by ten of each the next night and more, striving to achieve increasingly higher levels of physical activity and fitness.

The menstrual cycle and menopause were described as problematic by female participants.

> *When I was a young woman, I used to have this severe psychotic thing happen pre-menstrually. (P6)*

> *When I used to go off the deep end I usually had my periods. (P2)*

Seeman (2012a) reviewed research published between 1990 and the early 2000s on the relationship between schizophrenia and the menstrual cycle and concluded that rather than being an exacerbation of schizophrenia caused by the menstrual cycle, two separate syndromes are in operation; premenstrual symptoms added to psychotic symptoms and that both need to be treated separately. Oestrogen has emerged as an effective adjunct

treatment with antipsychotics during the pre-menstrual phase (Kulkarni 2009; Kulkarni et al. 2001).

Menopause was another significant time:

> *I got sick more often when I had menopause. I'm (age removed) now, when hormones aren't so up and down. In the last 4 years I have been very, very stable. (P2)*

> *About three years before the end of menopause I would get like a pre-menstrual sort of schizophrenic thing nearly 24 hours a day, seven days a week [...] I was a bit unstable nearly every day for a year or two, it was mild but constant. It's on the wane now and I am expecting to be less likely to feel irrational. (P6)*

Literature on living with schizophrenia while undergoing menopause is relatively sparse (Seeman 2012b). What is known is that the absorption of oral medications declines and therefore they are less effective (Seeman 2012b). However there is a reluctance on the part of physicians to discuss menstrual problems and menopause symptoms for women who live with mental illness and therefore the associated problems are poorly treated and remain a challenge for many women (Seeman 2012a).

The mental health system

Participant descriptions which have been identified as belonging to the element of *mental health system* are those which relate to experiences resulting from decisions and actions taken because of an overriding health system issue, policy or procedure linked with the provision of mental health services. These are distinct from being part of the therapeutic or non-therapeutic interaction of particular professionals. All participants spoke of their experiences of being hospitalised and treated within the health system. For some there were multiple occasions spanning many years.

Having experienced forced involuntary hospitalisation, it came as a surprise to some participants that when they had the insight to know that they did need help; they were unable to gain admission:

> *My brain was going so fast, it was me telling her I'm no good, I need to be in hospital, so what do you do in that situation? You knock on the door of [mental health unit] and actually what they tell you is to go away because that's not the way you get yourself into hospital and I didn't know that because every other time someone else had put me in there. [...] I had knocked on the door and been turned away. (P10)*

'No wrong door' is a principle that every door in the health care system should the 'right' door (Central Hume Primary Care Partnership 2006, p. 13). Under this principle, they could have been *carefully guided to the right door*, rather than being told to *go away*.

> *I went to outpatients and one doctor said that it wasn't a holiday house and he wasn't going to admit me, I went there two or three times, I went to [hospital] for help and really they didn't want any part of me because they wouldn't admit me. (P4)*

For participant four, admission was achieved eventually achieved through the intervention of a family member who held a significant rank in society:

> *I went there two or three times. It was my brother-in-law who talked the doctor into admitting me and I finally got the help that I wanted, that I needed. (P4)*

While being very grateful for the much needed admission, participant four felt disempowered by having their insight and self-advocacy invalidated by the system through their inability to achieve admission for themself. This was experience on numerous occasions:

> *Even the nurse in Sydney who took me off the [medication] he told me not to go there unless I had an appointment but I was desperate for help. (P4)*

As identified within the review of literature, people with a diagnosis of schizophrenia have traditionally experienced disempowerment, marginalisation and oppression

(Barker 2009a; McLean 1990; Pearson & Gerzon 2001). Participants in this study described many years of treatment within the health system. Much of this was early in their illness experiences, before the emergence of a recovery orientation in mental health clinical practice. Literature discussing that era described clients as passive recipients of diagnoses and passive respondents to treatment and the impact was described as destructive (Beecher 2009; Leggatt 2000). Again, for participants within this study, there were occasions when episodes of care within the health system were negative and challenging. Rapp and Gosha (2006) identified the potential consequences of these experiences as being an erosion of strength and self-confidence, loss of assertiveness and self-advocacy, a weakened sense of competence, an increased sense of vulnerability and ultimately loss of hope.

> *The first time I didn't think there was anything wrong with me except that I was brought to the hospital in the back of a paddy wagon [police van used for transporting people suspected of having committed a crime], you know there's no winners in that situation. (P9)*

> *I was in that cell and it was like, the saying goes, when you're truly naked in a cage and the whole world is laughing at you like that, when you have nothing…. (P10)*

Being transported by Police is an unfortunate but acceptable transport arrangement for people experiencing a crisis in their mental health within Australia (Police Federation of Australia 2005). Being secluded in a bare, locked room, located within hospitals, that has the appearance of a *cell,* is also a method of behavioural control used within the New South Wales Health System (Ministry of Health 2012).

The Wesley Mission conducted a study of homeless people living in Sydney, Australia and identified that 75 per cent of participants had a mental illness (Robinson 1998), 29 per cent of whom had a diagnosis of schizophrenia. Homelessness among people with schizophrenia has been linked with shortcomings of the health system such as under-

funding and fragmented and poorly monitored community based services which severely challenge the ability to provide ongoing help (Parker, Limbers & McKeon 2002). Within NSW, the Housing and Accommodation Support Initiative (Muir et al. 2008) was created with the aim of addressing, among other things, the problem of homelessness following discharge from inpatient settings which was described by participant nine.

> *They just kept me for 3 days and they discharged me to a homeless state and so that hopefully that wouldn't happen today. (P9)*

The stressful impact of planned closure of support services was also mentioned:

> *When they were talking about closing down [support service] I think I ended up being sicker instead of getting well. (P2)*

For some participants, the meaning of resilience was that they did not follow the advice of a mental health service:

> *It's not giving in to mental health and how they suggested I should have gone on disabilities pension I tried something else. That's what I call being resilient. (P11)*

The need to work with the health system and mental health services was viewed as critical and therefore the associated challenges were ones that needed to be overcome:

> *I'm under no illusions. My survival depended (and depends) on other things beyond my ability to influence [such as] institutions, medicine [...], and of course whatever other unrelated factors may influence life and test a person's resolve or will. (P8)*

Mental health professionals

Yet another element that emerged was that which related to mental health professionals. Participant descriptions of professional help highlighted how there was an initial sense of trust, based on attitudes inherited from parents:

I credit my mother with that because as a child we had a family doctor and if I got sick my mother would take me to the doctor and I would get medicine and treatment and so I feel like from an early age knowing that when you get sick you go to the doctor and you get treated, so I always had that respect. (P6)

However this trust eroded with experiences of feeling stigmatised:

I suppose originally I felt so ashamed so I started telling me by voicing it back then and then I was told by the doctor never to tell anyone and so I would actually never tell anyone. (P10)

Advice given by professionals was heard by participants but was ignored:

The advice of my case worker at the time who I'd been ignoring and wishing he'd go away. (P8)

Professionals were described as going along patiently beside these attitudes, while continuing to provide advice. At some point, the advice started to filter through, was perceived as helpful and later descriptions by participants indicate feelings of partnership. Instead of feeling managed by professionals participants described how they chose to use the services of professionals:

I called in the mental health team, the local mental health team and they gave me some sleeping tablets, two or three days' supply and I got a bit of sleep and well I just kept going. (P3)

I went and saw a GP in [town] and he basically put me on the mental health plan and I see a psychologist and he suggested I up my medication a bit and just to see how that went and go back and tell him and it's gone, it seemed to work pretty well. (P11)

I'd ring mental health and just get a bit of counselling on the phone and they helped me. As time went on I got better and better and the counsellors taught me how to control different feelings. (P4)

Things that were helpful were brief interventions over the phone to address early warning signs and counselling sessions that helped participants to understand themselves and their families.

I've had many years of counselling and I know myself now a bit better than what I did when I was young. (P6)

It's only been in the last couple of years since I spoke to Dr […] that it's actually come to help and understand my parents. (P13)

It's funny because my case worker […] is now the case worker for a lot of my clients and I used to be sitting on this side of the thing and now I'm on that side […] and my wife noticed me becoming a bit unwell last year and I went and seen him and maybe it was because I was unwell but I thought he didn't want to help. (P11)

In an examination of the topic of invisible power within the practice of psychiatry and mental health nursing, Cutcliffe and Happell (2009) identified that power is embedded within particular speech acts which are designed to exercise control and yet that power and control is not overtly visible. An Australian study of the challenges faced by ten consumer consultants working in a mental health clinical setting conducted by Middleton, Stanton and Renouf (2004) revealed that they sometimes felt patronised and experienced open hostility, suspicion and disrespectful attitudes from professionals. Cleary et al (2011) and Cleary, Walter and Escott (2006) also examined the role of consumer professionals working in mental health settings and identified that experiencing role confusion, feeling stigma and discrimination from health professionals and the need to manage dual relationships impacted on their emotional well-being. Participants in this research identified how they were able to overcome the challenges and address their need for help by establishing new supportive relationships:

He didn't want to help so I went and saw a GP in [town] and he basically put me on the mental health plan and I see a psychologist. (P11)

In the Tooth et al study (2003) of important recovery factors for sixty Australian people living with schizophrenia, the role of health professionals was viewed as negative by 61 per cent of participants and as supportive by 39 per cent of participants. Negative actions included stripping hope by using language such as "you can't", by not valuing

consumer's experiences and by focussing on symptoms and problems rather than strengths and solutions (Tooth et al. 2003). Positive views were held in relation to experiences with particular professionals that were viewed as being hope based and supportive.

A Swiss examination of the attitudes of 1,073 mental health professionals and 1,737 members of the public towards a group of people with mental illness and a control group without mental illness (Nordt, Rössler & Lauber 2006) revealed that professionals hold as many stereotypes about mental illness as the general public do, however professionals are less willing to accept social restrictions based on using these stereotypes. Furthermore, professionals prefer to maintain the same social distance from people living with a mental illness as members of the public, with schizophrenia having the highest level of social distance when compared with other illnesses such as depression.

From participant descriptions of the meaning of resilience for people who experience schizophrenia, eleven different areas of experience were identified as meaningful and these were extracted and labelled as elements. The elements were medication, family, work, stimulation, stress, social ties, stigma, lifestyle, physical health, the mental health system and mental health professionals. This chapter discussed each of these elements and quotes from participant descriptions were used to provide connection with the essence of the experience. Further to this, relevant research and literature has been included to add strength and resonance with this study. The next section of this work will discuss the deeper interpretation of the way in which the elements are woven within the journey of schizophrenia.

The support and challenge dynamic

The elements presented in the previous discussion were described in both supportive and challenging terms by participants. For example, medication was supportive but also challenging, suggesting the existence of tension within the same element. The elements of family, work, social ties, physical health and experiences with mental health professionals were also described as both supportive and challenging. Figure 10 provides a simple illustration to allow visualisation for how the support and challenge dynamic nests within the experience of schizophrenia.
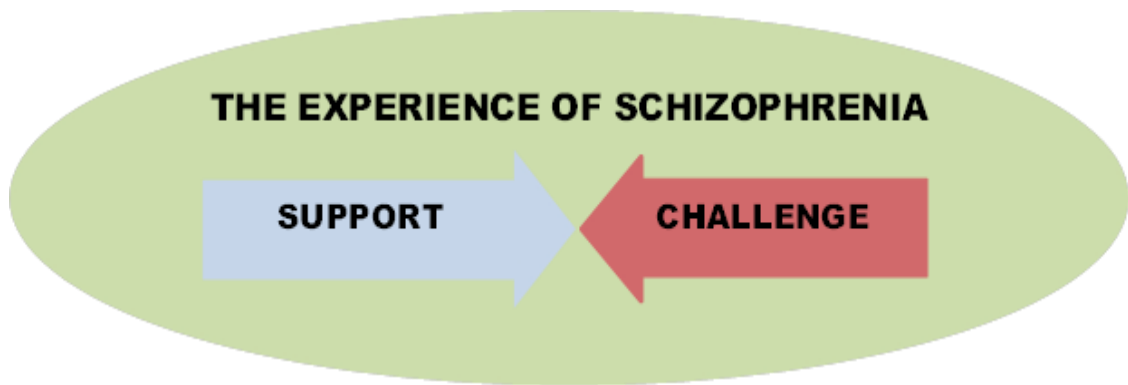
Figure 10: The support and challenge dynamic

Further to this, Table 23 lists the eleven elements discussed in the previous section and describes whether they were experienced as supportive or challenging, or both.

Table 23: Supportive and challenging elements

ELEMENT	SUPPORTIVE	CHALLENGING
Medication	✓	✓
Family	✓	✓
Work	✓	✓
Stimulation	✓	✗
Stress	✗	✓
Social ties	✓	✓
Stigma	✗	✓
Lifestyle	✓	✗
Physical health	✓	✓
The mental health system	✗	✓
Mental health professionals	✓	✓

The way in which this dynamic was experienced by participants is discussed next. The need to use the supportive side of the element meant that participants also needed to experience the challenging aspects. In the case of medications, needing medication to achieve relief from symptoms but not being able to tolerate the serious side effects caused a dilemma. Participants described being overwhelmed by the challenge of side effects and in the case of medication, this often meant cessation and becoming vulnerable to re-emergence of illness symptoms. Several participants described becoming unwell after they stopped their medication due to intolerable side effects. The experience of re-emergence of the illness eventually created for the participant the realisation of the need for medication despite the side effects to get the symptoms under control and to return to a desired state of living. These experiences 'forced' participants to take responsibility for sorting out and overcoming the challenges caused by medication side effects and also provided the motivation to do so.

The process of overcoming the challenge and using the supportive side to maintain a balanced state of health was an individual journey in terms of the amount of time it took. There were though common elements regarding the way in which participants overcame the specific challenges of schizophrenia. The way in which participants encountered the challenges and overcame them is discussed in more detail in a later section titled overcoming the challenges. But first, it is important to point out that the process of encountering adversity and successfully dealing with the challenge to emerge with improved function, as has been experienced by participants within this study, is consistent with the definitions of resilience shown in Table 24 and in particular, that of Richardson (2002, p. 34).

Table 24: Definitions for resilience

DEFINITIONS FOR RESILIENCE	
Resilience is a fluid process of adapting and prospering in the face of stress, which evolves over time and is influenced by context.	Becvar 2007
Resilience is the process of dealing with disruptive, stressful or challenging life events in a way that provides the individual with additional protective and coping skills than prior to the disruption that results from the event.	Richardson 2002, p. 34
An individual responding to stressful events through regaining equilibrium and growing healthily.	Reich, Zautra & Hall 2010
An individual's stability or quick recovery (or even growth) under significant adverse conditions.	Leipold & Greve 2009
The life-enhancing capacity to stay within the window of tolerance.	Siegel 1990

However, the meaning of resilience, as it emerged within this study, was not about the tension caused by the dual nature of some elements, but rather the way in which participants strove to, and were able to overcome the challenges.

> *This is about resilience, to being able to try again that you have failed. To see it as failure is wrong. You need to have another go. [...] Dignity of risk comes into resilience. When someone wants to make an adventure into the outside world someone will say "it's a risk we don't want you to do that" but having a go, to keep having a go and to get that education across to them, it's not going to happen the first time, you have to try and try and try. (P1)*

Resilience is about overcoming the challenge and not feeling and acting like a failure, but instead for people to keep trying, to persist and strive to overcome problems. The important energy within this overcoming of adversity was *striving*. The word *striving* means to make great effort to achieve or obtain something (Oxford University Press 2012) and the word *striving* captures and typifies the energy embedded in participant descriptions of overcoming challenges. The way in which striving was involved with overcoming the specific challenges has been considered and is described next.

The experience of schizophrenia

Each participant's experience of living with schizophrenia could be understood as a journey. Within this journey, while participants were undergoing the various challenges associated with schizophrenia, they also adopted particular approaches to tackling the challenges, made certain decisions and took a variety of actions. These were linked with experiences that occurred at particular points of dealing with the illness. There were similarities for the way in which these experiences occurred across this participant cohort and accordingly, these were placed within an overarching structural element.

Some experiences occurred early in the illness, for example, feeling like a victim of schizophrenia, and others occurred later, for example, taking responsibility for getting well. This was suggestive of changing views of themselves in relation to their illness, and interpretation of this resulted in three elements that encompassed the range of experiences such as self being lost within the experience of schizophrenia, self as struggling to deal with the illness and the self as separate and feeling a degree of control over the illness experience.

The essence of these experiences has been captured and described and has been synthesised into a depiction of the journey which is shown in Figure 11.
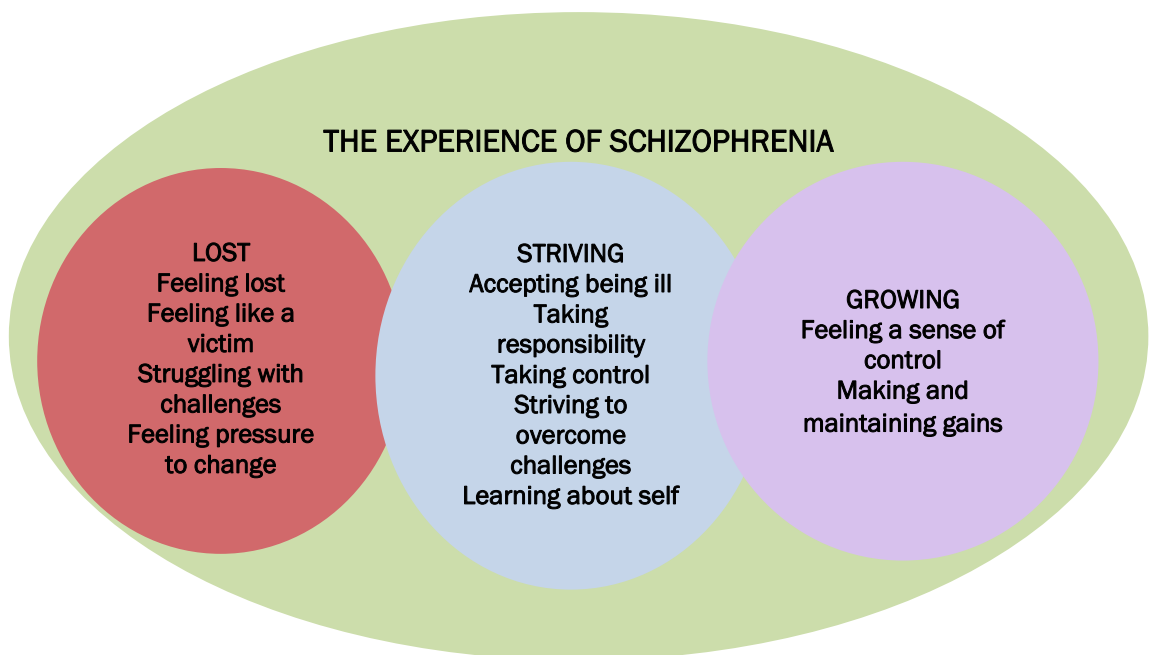
Figure 11: The experience of schizophrenia

A discussion in greater depth, of the experiences of schizophrenia, as described within the elements of lost, striving and growing, will now follow.

Lost

Figure 12: Lost within the experience of schizohrenia

The experience of feeling lost, feeling like a victim of schizophrenia, feeling unable to control the illness and of struggling with challenges while feeling pressure from others to change, was described for some participants as lasting for years.

Feeling lost

> *All of a sudden you're hearing voices and hallucinating and you think what the hell's happening? (P4)*

> *Things fell apart [...] disconnecting from all that support, [...] there was clearly something wrong with me, I lost my car and my job, my apprenticeship. (P10)*

> *I was homeless for five years, I lived in a tent. (P9)*

> *Ever since the 60s I have had one admission every decade. [...] I might not have married [wife named] and I mean that could so easily not have happened and I don't know where I'd be. I wouldn't be here. (P3)*

Some participants actively attempted to end their own lives during this period of being lost in the illness:

> *I've attempted suicide. I was taking 10 and 14 tablets at a time because I decided enough is enough. (P13)*

> *I was brought back to life twice from pretty serious suicide attempts. I was
> beyond suicide, I was dead, I didn't care if I killed myself, I was starting to
> break down, a mess, so wounded. (P10)*

People with schizophrenia are 25 times more likely to die than the average Australian.

Forty per cent of people with schizophrenia will make at least one suicide attempt and

10 per cent will suicide (SANE 2000).

Feeling like a victim

Being stuck in the role of feeling like a victim of schizophrenia was the reason

participants believed that they struggled and remained lost within with the illness.

> *Adopting the victim role [...] poor me, the victim, it's God's fault and it's
> somebody else's fault. Having an attitude where you don't take on the
> victim role is important. (P1)*

> *There definitely were periods of self-pity and shaking my fist at the heavens
> and that sort of thing. Perfectly normal I guess. Maybe I needed a long
> stint in self-pity before I could snap out of it and try to participate actively
> in life again. (P8)*

> *I've learned self-pity is a very, very dangerous thing to indulge in, it just
> keeps you right where you are and it's comforting and so you stay right
> where you are and have no impulse to better yourself because it's all
> someone else's fault or beyond your control. (P13)*

> *Any encouragement of victim mentality, self-pity, is decidedly
> counterproductive I found. (P8)*

> *One of the mechanisms of the victim is to feel sorry for yourself. That is a
> really basic attitude. I feel sorry for myself, poor me. This is something
> that holds you back. As long as you are asking 'why me' and saying 'poor
> me' you will be held back from taking on what is to be your own
> management of your own problems. Even if it is not your own fault in a
> philosophical sense, nobody can do it except for you. (P1)*

Being lost within the illness can be understood using two differing perspectives.

Estroff (1989) writes that schizophrenia is an "I am" illness which overtakes and

redefines the identity of the person and changes their relationship between the self and

sickness. Their sense of identity and the experience of positive social roles are lost. Sass and Parnas (2003) explain it as an exaggerated self-consciousness in which self is viewed as an external object which then may or may not exist and which research has shown, is associated with a weakened sense of action.

> *Mental illness is a very selfish thing, it's hard to say but it's very selfish, very consuming, don't let your illness consume you. (P10)*

Feeling pressure to change

Participants described there were times when someone, usually a family member, made a concerted effort to deliver a message about the need to accept the fact that they were ill and to change in some way.

> *My brother spent three months talking to me about being a victim. He banged his fists, he just didn't talk, he made his point really solidly. My brother forced me to run through a door. (P1)*

Messages from others about the need to change were heard but not necessarily acted upon until later:

> *I haven't always made good decisions to go with people but people have prevailed and been patient and I have eventually gone along [...] but if it had been left to me, I probably wouldn't have. (P3)*

Education and encouragement from mental health professionals, while not always appreciated at the time of delivery, were also acted upon later:

> *Listening to the advice of my case worker at the time who I'd been ignoring and wishing he'd go away [....] up until then [...] I pushed them away and did not want to be helped. (P8)*

Friends provided encouragement and tried to stimulate insight:

> *A good friend of mine said to me 'there's no rock bottom, it's a bottomless pit, depends on how much strength you've got to pull yourself out of the hole, there's always a hand to grab, make sure it's the right one'. (P10)*

Despite feeling under pressure to change, change occurred in its' own time, when the individual was ready. This is consistent with understanding the way in which people change according to the Transtheoretical Model of Change (Prochaska 2008), illustrated in Figure 13. Within that model, the stages of change are pre-contemplation, contemplation, preparation, action and maintenance and relapse (Prochaska 2008).
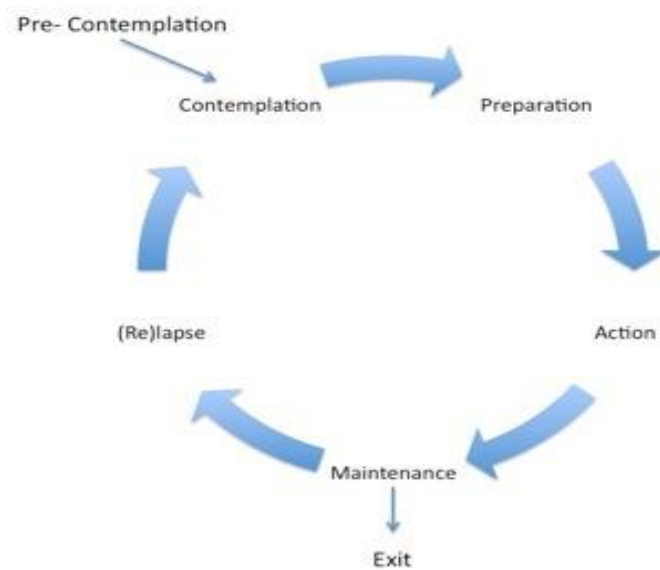
Figure 13: Transtheoretical Model of change

Descriptions provided by participants within this study, particularly within the element of feeling lost, are indicative of the pre-contemplation stage of change, where awareness of the ability to change lived experience may not yet have arrived (Prochaska 2008).

Struggling with challenges

The challenges that participants described as struggling with included; medication side effects, changes in hormone levels related to the female menstrual cycle, coping with stress, feeling stigmatised, having difficulties in relationships, significant changes to the services provided by mental health services and the stress of working.

Receiving a diagnosis of schizophrenia was described as a relief for some through having a way to understand their experiences but also as overwhelming and disempowering for others. Disempowerment and alienation can occur through transference of the beliefs of the clinicians, particularly if they are without hope and practice with a pessimistic attitude (Cohen & Cohen 1984) which transfers to the person being diagnosed (Bleuler 1978; Kelly & Gamble 2005; Leggatt 2000). This was the experience of Patricia Deegan (1994, p. 55) 'we were told we had an incurable malady and that we would be sick or disabled for the rest of our lives'. Having such an experience contributes to losing hope and feeling like a victim of schizophrenia.

Striving

STRIVING
Deciding to change
Taking responsibility
Taking control
Striving to overcome challenges
Learning about self and illness

Figure 14: Striving within the experience of schizophrenia

Shifting perspective, such as moving from feeling pressure to change to deciding to change involved a realisation, one linked with an awakening, followed by taking actions, was symbolic of a turning point. Rutter (2006a) is of the opinion that turning points alter life's trajectory because they open or close important opportunities, bring lasting change and affect the level of control people have over their lives. Participants one, eight and ten described having these experiences:

I met up with some American girl who gave me enough drugs to kill a battle ship and that was a massive wake-up call and I was near death and the only choice I had was darkness and I realised the light was life and I fought my way back and I was actually battering on death's front door. (P10)

I realised it starts off with a glass of water and eating right and when I did this I started to work on my physical, gradually, my emotions, my mental, and then I remember doing one push up and the next night I did another one and then I'd go up to 140 and then I added 140 sit ups on the kitchen floor. (P10)

I have been to gaol and there was a time when the only thing that really inspired me was being able to hear a Pee Wee calling outside the cells of the gaol. Dad and I used to be in the yard together and he'd look for the grubs and feed the Pee Wees. That then reawakened hope at a dark time. I can recover and I can beat this problem. (P1)

Words, slogans, speeches weren't what convinced me. Nothing actually did. At some point I snapped out of it and that seems to be all there was to it. (P8)

Participants imparted the sense that while turning points were experienced and actions to change followed, it wasn't until a retrospective view was taken that it could be seen as a turning point and the changes that had followed were able to be acknowledged.

Deciding to change

Participants described the shifting ground around the turning point:

I think there's always been a hand reaching out, it's just whether you accept the offer, it's always there, the offer to better yourself for improvement. (P10)

I started to challenge myself rather than give up on myself and say I do have goals. (P10)

So having been handed opportunities and good fortune on a platter, at some point I decided to accept the gifts and run with them, after rejecting them for a time and wallowing (with parents to support me, of course), that's all there is to it. (P8)

I thought I must be inadequate and maladjusted to life and I can grow and it turned my life around. (P3)

Some participants wanted to change to prevent the illness from affecting others:

> *I wanted to do it for my kids; I wanted to get them a stable life. (P4)*

Taking responsibility

The decision to take responsibility was described as a process of *'being willing'* and of *'learning to'*:

> *Being willing to step outside and try and climb out of that rut myself was another aspect [...] there comes a point where you have to try to meet your treatment half way and at least give it a chance to work even if it's unpleasant. (P13)*

> *There is a process to learning to take responsibility. Someone can't just show it to you. It was very hard to get rid of the victim mentality. (P1)*

The need to take control and to make changes came next:

Taking control

Taking control is an attitude that sets the stage for being able to then take actions to achieve control:

> *I think taking control is a gradual thing actually. (P6)*

> *It's best to take control of those things you can control. (P8)*

> *As time went on, and I got better and better, and the counsellors taught me how to control different feelings. (P4)*

> *It took a while to get there and I think felt a lot of power when I quit smoking, more in control of my life [...] it was a big change but I felt a greater control of my life. Then I managed to quit other things. (P12)*

Striving to overcome challenges

Rich descriptions of the attitude of striving to overcome challenges were provided by most participants:

This is about resilience, to being able to try again that you have failed. To see it as failure is wrong. You need to have another go and stigma goes against that when you fail everybody is judging you because of your mental illness. Dignity of risk comes into resilience. When someone wants to make an adventure into the outside world someone will say "it's a risk we don't want you to do that" but having a go, to keep having a go and to get that education across to them, it's not going to happen the first time, you have to try and try and try. (P1)

You just try things, I guess that was it, I wanted to be a normal person so I was willing to try things. (P12)

If I started to get symptoms, get out of bed and do what I have to do every day and that will make me well again but not if I don't take my medication, it won't work then. Get out of bed, have a shower, clean up the house, do the vacuum cleaning and do the things that need to be done, very important for staying well. (P5)

Find work, a hobby or exercise you have to try and try and try. (P1)

Life had backed me into a corner where I could only have very few options and I seized on writing as something to fill the time in the long slow medicated days with nothing to do so I started writing short stories at that point and I didn't think they were all that good and looking back at them they were really terrible {...} I stuck with it and put some effort in and [...] eventually I was able to get published. (P8)

Learning about self and the illness

Gaining knowledge about schizophrenia was considered to be an important part of the

journey:

So if I wanted to coax someone who had schizophrenia early in their life I would say get knowledgeable about it, read about it, read about the different medicines, what they do, read about the illness, what illnesses there are so that you can make informed decisions. (P6)

Things learned in grow – if I started to get symptoms, get out of bed and do what I have to do every day and that will make me well again, but not if I don't take my medication, it won't work then. Get out of bed, have a shower, clean up the house, do the vacuum cleaning and do the things that need to be done, very important for staying well. (P5)

Trying to get a schizophrenic to start helping themselves is a great help; to start studying themselves. Having access to some cues is great. Trying to understand ways that a schizophrenic speaks and thinks that's the hard

part because I've noticed myself that there's a distinct language barrier between us and yourselves. The way that we think, our structure of thought is completely different to a normal person. (P13)

Growing

Figure 15: Growing within the experience of schizophrenia

Growing was identified as a sense of being able to manage schizophrenia within daily life emerged and gains were made and maintained.

Feeling a sense of control

> *I have to balance work between home because I find if I do too many hours at work I can't cope with it. (P4)*

> *Taking my medication is important having a diet, eating properly, exercise - I pump a bit of iron, I jog a bit, I go on long walks. (P7)*

> *Appreciate the people around you, and I warn against taking things or people for granted but if you are in your comfort zone it is a hard thing to overcome, [...] I just have, hopefully, a continuous warning light going off but it keeps you on track. (P9)*

> *It took a while to get there and I think felt a lot of power when I quit smoking, more in control of my life and that sort of thing, it was a big change but I felt a greater control of my life. (P12)*

Making and maintaining gains

Once control had been taken and participants had striven for change, a period of growing followed, characterised by new attitudes, new activities, new associations, new social situations and a sense of being able to taken life on, alongside the experience of schizophrenia:

> I had to grow up, it took me a long time to grow up and I'm glad it happened because I was a redneck, stigmatising, racist little pig and I'm so pleased it's [schizophrenia] happened because it's opened my eyes and I wouldn't wish it on anyone. (P10)

> I don't know that my mother would have predicted my writing success; it looked at times like they'd be taking care of me the rest of my life and theirs so it was a very good thing to see them proud of their efforts. (P8)

> If I want to do something and I know when it starts off I might be awkward and that sort of thing but with a bit of practice you get better at it and it doesn't seem to take long and you can be very good at something pretty quick. I've learned to play the violin and the piano, I've taken both those things on this year so I'm very happy [...] it's a matter of picking things up and having a go and then having lessons consistently each week and practice. (P12)

> Know this you will get through and see the light, you'll feel a hundred foot tall [...] once you have gone through a few of them [challenges]and it's nothing to do with schizophrenia it's life what's happening to you, [...] for that brief moment when you have just broken through the last one you go 'bring it on, I'm ready', and you walk through that plateau like a rainforest and you know that mountain's coming and I don't stop, I face it now and I lock horns with people along the way but the gift of getting through the mountain is not telling other people to get out of the way, it's allowing them to take a bit of weight for you. (P10)

> I think one of my strongest points is a very strong world-view so understanding the picture and how as an individual, one of 6 ½ billion people on this planet I can make my contribution. [...] What is of most significance is your contribution to your family or your community or your society or your civilisation or whatever contribution you can make. My catch phrase is 'no innocent bystanders', everyone's involved, they're all our problems and we've got to work at it, this is my resilience. (P9)

The meaning of resilience within the experience of schizophrenia

Each participant provided a definition of the meaning of resilience for them. Their descriptions suggest that resilience in the context of schizophrenia is not smooth sailing through adversity but rather struggling against adversity to succeed, with the struggle involving many backward steps and falling over many times before getting control of the challenges.

> *This is about resilience .... have a go .... keep having a go ... to see it as failure is wrong ... you need to have another go ... it's not going to happen the first time you try; you have to try and try and try and try. (P1)*

Participant ten saw their resilience as being formed through a small community farming background involving supportive parents and friends and learning through playing junior league that if you fell down you had to get back up.   Participant ten stated that they had broken with these supports while they allowed themself to succumb to the adversity of schizophrenia but that the decision to take responsibility and control of their situation involved regenerating these support networks as well as building new ones.   Resilience was also linked resilience with accepting and using family and professional supports.

Resilience was also demonstrated by a decision not to go on to a disability support pension as was being advocated by the mental health case manager at the time and instead deciding to take responsibility for remaining independent and trying something different by seeking employment, which was achieved. Setting goals and not giving in to set backs also demonstrated resilience.

Participant fourteen stated resilience is *the power to stop or resist things*. Participant ten stated resilience is "the ability to find what you want to do and what you don't want to do" and participant seven stated resilience with schizophrenia involves:

> *Making a deliberate effort to stay well through things like taking medication and having a good diet. (P7)*

An overall meaning for resilience, for a person living with schizophrenia, was arrived at through a comprehensive process of thoughtful synthesis of all of the material presented; the eleven elements, the support and challenge dynamic, the experience of schizophrenia and the participant definitions for resilience. Figure 16 illustrates how the meaning of resilience has been synthesised and following that, Table 25 describes the meaning of resilience within the experience of schizophrenia.
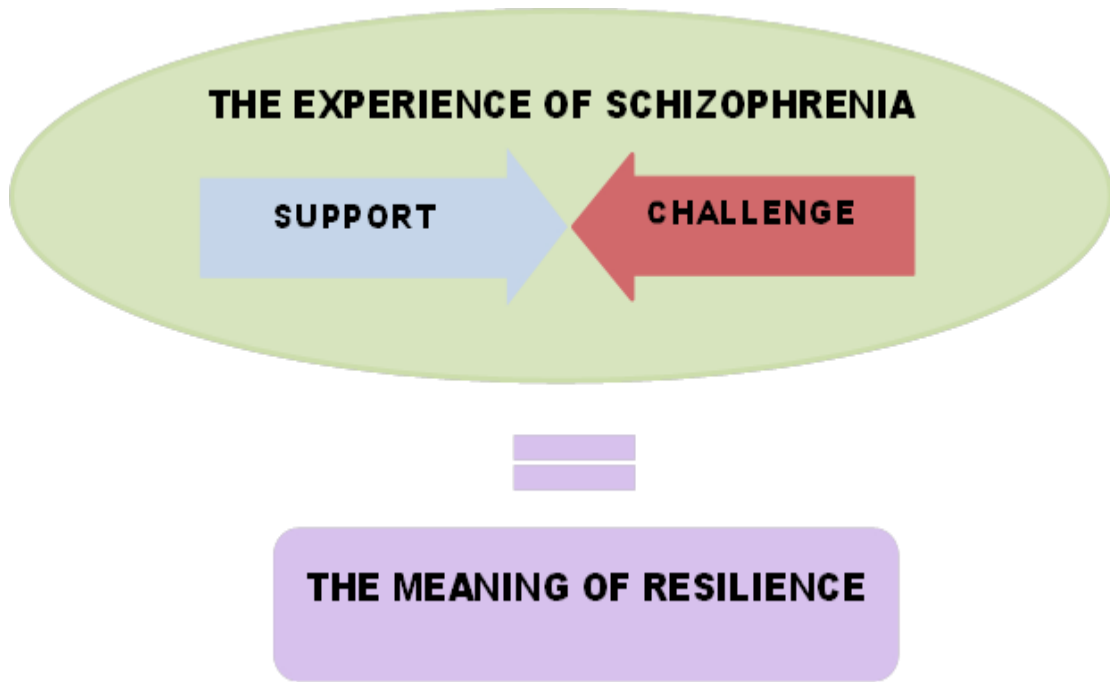
Figure 16: The synthesis of the meaning of resilience

Table 25: The meaning of resilience within the experience of schizophrenia

Resilience means adopting an attitude of striving to overcome the severe adversity caused by the experience of schizophrenia. The process of striving enables the person to learn about themselves, the effect of the schizophrenia illness on them, and how to manage it in the context of the life they want to live. Striving to overcome schizophrenia involves struggle, including repeated backwards steps and during this, the person seeks out and uses supportive people and resources. The process of seeking out and using support also comes with challenges and resilience emerges from the process of competently overcoming these, in the quest for improvement. The person then seeks out new challenges and experiences and grows life in ways unrelated to just living to manage the illness.

Conclusion

Schizophrenia is a mental illness characterised by undesirable schisms of mood, thought and behaviour that interfere with daily functioning (Mura 2012; Tandon, Nasrallah & Keshavan 2011). Symptom presentation has a high degree of variability and no two people will experience the same mix of symptoms in the same pattern. The cause is unknown and development of the illness is understood to result from the interplay of both genetics and stress from the social environment (van Os & Kapur 2009). Schizophrenia has a high cost both financially and in terms of burden for those who develop it and their families and the greater society in which they live (Knapp & Razzouk 2009; McCrone 2007; Rössler et al. 2005; Wolff 2007; World Health Organisation 2008b). Receiving a diagnosis of schizophrenia is a stigmatising burden that exposes the person to being judged, discredited and disempowered (Corrigan, Roe & Tsang 2011), however it has also been described as a welcome relief as it enables understanding of what has been happening and also facilitates access to appropriate treatment and support (Robertson & Walter 2007).

Prescribing medication to control symptoms has historically been the main treatment modality (Keshavan, Nasrallah & Tandon 2011) however this has now broadened out into a more person-centred approach that not only includes medications but also includes promoting recovery of the person within their greater life context (Barker & Buchanan-Barker 2011; Brennaman & Lobo 2011). The majority of people diagnosed with schizophrenia live a fulfilling life (Craze 2012; Levine et al. 2011; Lysaker, Roe & Buck 2010), a smaller percentage live with varying levels of symptoms and the remainder live with a level of symptoms that have a daily impact on their ability to function in the usual activities of living. Resilience is promoted within mental health

service planning as being important for influencing the outcome and for facilitating coping with the problems of living with mental illness and improving functioning (Commonwealth of Australia 2009; Craze 2012). Enhancing resilience is also promoted within practice standards for Australian mental health nurses (Australian College of Mental Health Nurses 2010).

Many definitions of resilience have been generated within other areas of study such as education and sport and many of these definitions describe an individual's ability to adapt in the face of serious stress or severe adversity and to emerge in an improved state (Wald et al. 2006). An improved state includes having developed additional strength, support or resources with which to face future challenges (Richardson 2011). However, the meaning of resilience in the context of mental illness and schizophrenia is little researched and poorly understood.

This research goes some way to filling this void by examining and understanding the lived experience of people with schizophrenia to interpret the meaning of resilience. Heidegger's phenomenology was adopted as the particular philosophy guiding the study. Ethical approval was received to personally interview fourteen consenting people with lived experience of schizophrenia and this occurred at a time and place of their choosing. Van Kaam's psychophenomenological method was used to analyse the data.

Findings indicate that within the experience of schizophrenia, the elements of family, work, stimulation, stress, social ties, stigma, lifestyle, physical health, the mental health system and mental health professionals were identified by participants as meaningful because they provided support within the journey of learning to live with the illness. Those elements also contained intrinsic challenges which had to be overcome in order

to use the support. Overcoming challenges, involved falling over, getting back up, not seeing it as failure, trying, trying and trying again, striving and achieving change.

The energy used to overcome the challenges was *striving*. Striving to overcome challenges, and actually being able to overcome them, while building support along the way, was central to the meaning of resilience provided by participants within this study and was also synonymous with definitions of resilience within existing literature. The meaning of resilience was embedded within the act of striving to overcome challenges. Therefore, challenging experiences are an important part of the meaning of resilience and are also important for learning how to manage schizophrenia.

The journey with schizophrenia was characterised by experiences of feeling *lost*, feeling like a victim of schizophrenia, struggling with challenges, feeling pressure to change, deciding to change, then *striving* to overcome challenges by taking responsibility, taking control and learning about self and the illness. What then followed, were feeling a sense of control and *growing* through making and maintaining gains. The experience of schizophrenia as articulated by participants in this research is aligned with consumer views of the experience with schizophrenia as being one that is a journey that includes maintaining a hopeful view, taking responsibility for self and striving to achieve a life that has purpose (Andresen, Oades & Caputi 2003; Craze 2012; Geanellos 2005; Lysaker, Roe & Buck 2010; Noiseux & Ricard 2008; Piat et al. 2009; Tooth et al. 2003; Warner 2009).

Schizophrenia is not a destination but rather a condition. It insists that a person take responsibility for overcoming the adversity it brings, to then transcend the illness and

achieve a life that is meaningful and rewarding. This manifests an ongoing opportunity for personal growth. The meaning of resilience is embedded within that journey.

This chapter has described the findings of research which explored the meaning of resilience for people who experience schizophrenia. Findings have been compared with what is known within found existing literature. The final chapter presents the contribution to knowledge, recommendations for consideration by mental health professionals and mental health services, recommendations for further research and the limitations of the study.

CHAPTER SIX

CONCLUDING STATEMENTS AND RECOMMENDATIONS

Introduction

The previous chapters presented an overview of the study, provided comprehensive background information, and justification of the research design as well as a presentation of the findings and discussion of these in the context of external literature. This chapter then, summarises the overarching goal and aim of the research and offers some further contributions to knowledge and it also makes some recommendations for practice for consideration by mental health professionals, some considerations for mental health service delivery and offers some recommendations for future research. Limitations of the study are discussed and recommendations for further studies are made.

The overarching goal of this research was to contribute new knowledge. This was achieved by fulfilling the aim of the research which was to understand the meaning of resilience for people who experience the illness known as schizophrenia. The impetus for undertaking the study was to privilege the voices of the silent and present their meaning of resilience within the context of their lived experience of schizophrenia. The research was designed in such a way therefore to answer the question of *what is the meaning of resilience for people who experience schizophrenia* with findings indicating that the meaning of resilience is embedded within striving to overcome the challenges brought about by schizophrenia in order to build support and to grow life in ways unrelated to just living to manage the illness.

Contribution to knowledge

Building the resilience of people who live with mental illness has figured prominently in the planning for mental health service delivery in Australia since 2003 (Australian Health Ministers 2003; Council of Australian Governments 2006; Craze 2012) and is part of the standards of practice for mental health nurses (Australian College of Mental Health Nurses 2010). Many definitions of resilience have emerged from research in the areas of education, psychology and sport. However, very little is known about the meaning of resilience in the context of mental illness (Hanson & Gottesman 2012). Researchers have identified that resilience needs to be explored from within the context to which it will ultimately be applied because each experience has its own unique dynamic and its own unique adversities (Luthar, Sawyer & Brown 2006; Masten 2007; Rutter 2006b). Therefore, building resilience for a person with schizophrenia, as is prescribed via mental health service planning and professional standards for nursing care, requires practice knowledge which is specific to resilience and schizophrenia, and this currently does not exist. Mental health professionals will find it very difficult to work with people to build resilience if there are no evidence-based definitions or frameworks for doing so.

This research did not though set out to identify what builds resilience. However, the starting point for constructing a base of evidence on which to assist consumers build resilience is to determine what resilience means for them; in this case this was done within the context of the person living with schizophrenia. By understanding the meaning of resilience for people who experience schizophrenia, this study provides an important contribution towards building the evidence. The findings may also be useful

for people who live with schizophrenia to understand the meaning and value of resilience for others who share a similar journey.

Considerations for mental health professionals and mental health service delivery

1) Mental health professionals must consistently deliver hopeful messages within treatment and education for people experiencing schizophrenia while at the same time appreciating that the knowledge provided will be used when individuals are ready to use it and not necessarily at the time of delivery. Hope is the foundation of recovery so it is important to understand that while it may not appear to be making any impact, it is never a wasted effort. One cannot build resilience if hope is not a component.

2) Change needs to be valued and seen as an ever-present part of the experience of living with schizophrenia. The person is on a journey that starts with feelings of disempowerment but it is vital to recognise that consumers do find their way to empowerment, in their own time. A necessary part of expressing empowerment is *choosing to use* health professionals and services, rather than being passive recipients of care. Therefore, it is important for the attitude of professionals and services to be one of acceptance while demonstrating a positive response to this need.

3) Whilst stimulating and rewarding activities and meaningful social ties are important for the meaning of resilience, just as they are embedded within recovery, those described by participants within this study evolved from each individual's own passions and interests, rather than being prescribed by a

service. Lack of participation in service driven activities should not be considered to mean lack of interest in activities or a lack of motivation. Mental health professionals need to strive to connect with each consumer's own stimulating and meaningful interests.

4) Being challenged, which may include taking risks, is an essential element of the meaning of resilience for people who experience schizophrenia and therefore services and professionals need to be supportive of challenging experiences and their associated risks, rather than taking action to prevent them. Challenges and some risk need to be viewed as opportunities.

5) Services and professionals need to work <u>with</u> consumers if they are closing services and restructuring therapeutic relationships to maintain support while they are simultaneously also creating a significant challenge for consumers.

6) Being lost within schizophrenia and feeling like a victim is a part of the journey, as is falling over and taking backward steps while striving to overcome challenges. These experiences are not fixed symptoms of the schizophrenia illness, nor are they indicative of the character of the person. They need to be viewed as important elements within the meaning of resilience and should be considered to be part of the journey rather than as problems.

7) Resilience may not be something that can easily be 'built' or facilitated within a specific encounter, program or time frame. It is a complex connection of attitudes, energy and experiences which play out amidst a unique set of social

factors within a highly personal journey. Therefore, the meaning of resilience is embedded within the individual world of the person with schizophrenia and 'building' resilience may not be a 'deliverable' outcome. It is more like a challenging space that is opened up in which something may grow and then again, it may not, at that time. Based on the meaning of resilience interpreted within this study, 'building' resilience may not be a realistic 'outcome' of an episode of service provision.

8) Mental health systems and mental health professionals play an important part in the experience of schizophrenia for the person who is living with this illness and it is important to be responsive to consumer driven needs for support, rather than primarily responding through system driven capacity.

Recommendations for further research work

1) Whilst this particular study explored the experiences of consumers, it was apparent that services and professionals have also been required to undergo a journey of changing their views of schizophrenia and the people who are diagnosed with it. A qualitative study to explore the meaning of resilience in the context of schizophrenia for mental health professionals would be important for understanding the underlying beliefs of the professionals who are required by their services to participate in activities aimed at resilience building. Both meanings should be considered in the design of any future efforts aimed at building resilience.

2) Having identified that challenge is important and meaningful to resilience, rather than something to be avoided, it would be useful to extend the view further into the symptom experience of schizophrenia to know whether symptoms have specific meaning and importance and what that meaning may be. For example, decreased motivation, isolation, heightened sensory perception, delusional thoughts, intrusive thoughts and suicidal ideation. Are they experiences to be avoided at all costs or are they important and meaningful challenges and do they also have a role in the meaning of resilience?

3) A deeper understanding of the way in which people with schizophrenia have overcome specific challenges related to the journey would be useful for other consumers, professionals and health services.

4) Exploration of the meaning of the role played within family by people who experience schizophrenia is necessary, particularly with a view to positive aspects.

Limitations

1) Within the psychophenomenological method of analysis used within this study, the researcher was required to remain separate and to critically reflect upon self for the purpose of declaring the potential impact and influence upon the research findings. Whilst the way in which this was attended to has been explained in chapter three and concerted efforts have been made to do this, I concur with the findings of experiments within quantum mechanics that show that it is impossible to separate experimenter and experiment because the world is not

made up of separate objects but instead is an intimate connection of vibrations of energy and relationships (Greene 2003). Therefore, whilst all precautions advised within the chosen research method were undertaken, separation of my influence from the eventual findings is not totally possible and thus is an important consideration. (Padgett 2008; Schwandt 2001).

2) The researcher carried out a significant amount of reading to explore using stories of experience as research data (Adame & Knudson 2007; Chadwick 2007; Churchill 2002; Frank 1995; Palmier-Claus et al. 2011; Ridgway 2001; Schwandt 2001; Young 2009), and also, the role of reflection, awareness, consciousness and truth in the construction of meaning (Fabun 1968; Farchaus Stein 2011; Geyer 1916; Newman 1994; Pereira 2012; Perkins 1952; Rolfe, Freshwater & Jasper 2001; Siegel 1999; Vajda n.d.; van Manen 1997). The understanding derived from this reading, and which was taken into the interpretation of findings was that a researcher is not the official gatekeeper on what is real and what is not and the meaning provided by participants was honoured as being the truth of their experience. Therefore, the transferability of these findings needs to be considered in light of this (Lincoln & Guba 1985; Polkinghorne 2007; Shenton 2004).

3) Polkinghorne (2007) cautions that language is limited in its ability to capture the complexity and depth of experienced meaning. Furthermore, the researcher may not be able to capture meaning that sits outside of awareness. Within this research, participants' voices were used wherever possible to allow the reader to

examine the link between participant descriptions and the researcher's subsequent interpretation of meaning.

4) Use of a single observer within this study means that the findings are from the observation of one, albeit with supervision, rather than through the agreement of multiple observers. Use of more than one participant and the interpretation of multiple individual experiences do however strengthen this limitation (Polkinghorne 2007).

5) Whilst the sample size of 14 is acceptable for phenomenological research methodology, it does not produce generalisable results but instead, a 'sufficiently probable' outcome. It was not the intent to generalise findings but contribute knowledge that most strongly relates to those who provided the experiences.

This chapter discussed the need for mental health professionals and mental health services to view schizophrenia as a journey of challenge and change within which the most useful attitude to adopt is one of considering some risk and most challenges as important opportunities. Furthermore, delivering positive, supportive and realistic messages, even though people may not be ready to embrace them, is essential. The paradigm is shifting beneath all; consumers, professionals and services. The need to build the resilience of mental health consumers is a leading component of this shifting paradigm and therefore much research is needed to begin to understand what may be involved in supporting this.

Final statement

Schizophrenia is not a destination but rather a condition that insists that a person take responsibility for overcoming the adversity it brings, to then transcend the illness and achieve a life that is meaningful and rewarding and manifests an ongoing opportunity for personal growth. The meaning of resilience is intimately linked with the energy of striving that is embedded within the journey with schizophrenia.

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Appendix 1: UOW HREC approval letter

University of Wollongong

INITIAL APPLICATION APPROVAL
In reply please quote: **HE07/320**
Further Enquiries Phone: 4221 4457

26 March 2008

Ms Susan Liersch
School of Nursing, Midwifery, & Indigenous Health
University of Wollongong

Dear Ms Liersch,

Thank you for your correspondence of 12 March 2008 responding to the HREC of the application below. I am pleased to advise that the application has been **approved.**

Please note the following:

    i. Information about mandatory reporting conditions and follow up must be included in the Participant Information Sheet. Please forward the revised document to the HREC before commencing research.

    ii. In the second paragraph of the 'Method and Demands on Participants' section of the Participant Information Sheet you need to change "their" to read "your".

Ethics Number:	HE07/320
Project Title	Exploring the meaning of resilience for people diagnosed with schizophrenia
Name of Researchers:	Ms Susan Liersch, A/Prof Janette Curtis, Dr Peter Caputi
Approval Date:	20 March 2008
Expiry Date:	19 March 2009

The University of Wollongong/SESIAHS Health and Medical HREC is constituted and functions in accordance with the NHMRC *National Statement on Ethical Conduct in Human Research.* The HREC has reviewed the research proposal for compliance with the *National Statement* and approval of this project is conditional upon your continuing compliance with this document. As evidence of continuing compliance, the Human Research Ethics Committee requires that researchers immediately report:

- proposed changes to the protocol including changes to investigators involved
- serious or unexpected adverse effects on participants
- unforseen events that might affect continued ethical acceptability of the project.

You are also required to complete monitoring reports annually and at the end of your project. These reports are sent out approximately 6 weeks prior to the date your ethics approval expires. The reports must be completed, signed by the appropriate Head of Unit, and returned to the Research Services Office prior to the expiry date.

Yours Sincerely,

A/Professor Arthur Jenkins
Chairperson
Human Research Ethics Committee

cc: A/Prof Janette Curtis, Nursing

Appendix 2: GSAHS approval letter

13 December 2007

HREC reference number: 07/GSAHS/20

Mrs Susan A Liersch
School of Nursing, Midwifery and Indigenous Health
The University of Wollongong
Northfields Avenue
WOLLONGONG NSW 2550

Dear Mrs Liersch,

HREC reference number: 07/GSAHS/20
Project title: 'Exploring the meaning of resilience for people living with schizophrenia.'

Thank you for submitting the above project for single ethical and scientific review. This project was first considered by the GSAHS HREC at its meeting held on 06 December 2007. This HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

I am pleased to advise that the Committee has granted ethical approval of this research project. The documents reviewed and approved include:

- Application
- Interview Schedules / Topic Guides
- Letter of invitation to participant
- Master Consent Form
- Master Participant Information Sheet

Please note the following conditions of approval apply (note the following items, at point 1, will refer to sections of the NHMRC document the *National Statement on Ethical Conduct in Human Research*, 2007 (NS) where applicable).

1.   Ethical considerations and changes required to NEAF and attachments

NEAF

- At items 3.11a and 3.22 you have stated that the information will be both de-identified and potentially identifiable. Please clarify or make consistent.

**Better Health for
Rural Australia**

- At 3.18 you have identified that you will use a password-protected memory stick for backup. Please also indicate how you will prevent loss/ ensure safety of the memory stick. This is in accordance with chapter 2.1 of the NS, in particular the statements on harm related to potential disclosure of information.

- At 5.9-12, under 'recruitment', you have discussed the role of Community Case Managers in screening to identify people who fall within the recruitment criteria. In accordance with NS section 1.1 (research merit and integrity) and NS chapter 5.2.5-6 (researcher responsibilities), please provide a copy of the information, (for example a checklist or instruction sheet) that you will be providing to the case managers to assist them.

- The HREC recognises that you will exclude Aboriginal and Torres Strait Islander people from the study (as indicated at 1.4 and 5.3-4), and advises that this should be clearly stated when you publish your findings. The HREC would encourage you to discuss with your supervisor the impact that excluding Aboriginal and Torres Strait Islander people from the study might have in relation to equity issues in health care. This relates to the core principle of Justice in research, as discussed in the NS at section 1.4.

Consent form and participant information sheet

- On the consent form, it is advised that you give an indication to participants that they can choose not to answer some questions. This is in accordance with the principles behind the 'guidelines for consent' in the NS at chapter 2.2.1-2.2.6.

- At 3.44 and 5.5 you have identified that participants can withdraw consent up to the point of data de-identification. In accordance with NS 2.2.2 please either clearly indicate this statement on the patient information sheet and consent form OR identify an audit trail method whereby participant information *can* be withdrawn, even after coding (NS chapter 2.2.1-2.2.6 and NS chapter 2.2.20).

- GSAHS HREC details should be included on PIS. Complaints may be directed to: Executive Officer, GSAHS HREC, PO Box 3095, Albury 2640. (phone 6080 8900 fax 6080 8999;)

- Notification of proposed research sheet. Clarify the purpose of this form as it appears to be surplus to requirements. If this form is needed it should be rewritten in lay language. Also provide clarification of release of data list as described in paragraph 5 as this needs to be consistent with methods described in NEAF form (5.16) where it states that researcher will not know who has been invited to participate.

Please send amended NEAF and attachments, along with an explanatory letter indicating how you have addressed each of the above points, to the HREC Executive Officer, Alison MacTaggart Lamb.

2.   The co-ordinating investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including: unforeseen events that might affect continued ethical acceptability of the project.

3.   Proposed changes to the research protocol, conduct of the research, or length of HREC approval will be provided to the HREC for review in the specified format.

4.   The HREC will be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.

5.   The co-ordinating investigator will provide an annual report to the HREC and at completion of the study in the specified format.
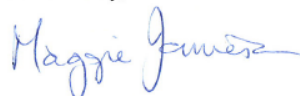
HREC approval is valid for 3 years from the date of this letter.

Should you have any queries about the HREC's consideration of your project please contact Ms Alison MacTaggart Lamb, Executive Officer of the HREC, on email Alison.MacTaggart@gsahs.health.nsw.gov.au or (02) 6492 9199.

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained through a Site Specific Assessment.

The HREC wishes you every success in your research.

Yours sincerely,

Dr Maggie Jamieson
HREC Chair
Greater Southern Area Health Service

Appendix 3: Invitation to participate

<u>NOTIFICATION OF PROPOSED RESEARCH PROJECT</u>
<u>AND INVITATION TO PARTICPATE</u>

'The meaning of resilience for people who experience schizophrenia'

Permission has been granted by the Greater Southern Area Health Service to conduct a research project involving the participation of consumers of the mental health service. The aim of the research is to identify the meaning of resilience for people who experience schizophrenia. Resilience has been identified in literature as an important quality for positive outcomes for people who experience adversity and has been studied in many areas of life, including; adolescent development, education and recovery from illness.

This study has been designed to find out firstly, the meaning of resilience for people who experience schizophrenia. The researcher will produce a major thesis based on this to fulfil the requirements for the awarding of a Doctor of Philosophy degree. The research will be conducted by Sue Liersch, who is currently working within the Greater Southern Area Health Service at an acute inpatient mental health unit as a registered nurse and who also works concurrently with the University of Wollongong as a Lecturer in Nursing, teaching the mental health curriculum to undergraduate nursing students.

The research process involves an individual confidential interview with consenting participants during which each participant will be encouraged to explore and reveal individual beliefs and experiences relating to resilience in the journey with schizophrenia. Recorded interviews of approximately 60 minutes duration will be conducted in a private room at the nearest public hospital or other venue as agreed between researcher and participant giving full consideration to safety and confidentiality of both parties.

Participation is on a voluntary basis following initial invitation to participate and there is no obligation on any invited person to participate. Your decision to consent or decline to participate will remain confidential to the researcher and will not be made known to the area health service. There are no consequences for continued provision of care from the Greater Southern Area Mental Health Service or any other part of the health service for a decision not to participate.

'The meaning of resilience for people who experience schizophrenia'

Participants names will be coded and attached to interview data and the actual name will be known only to the researcher. Names of actual participants will not be associated with any published research data.

Interviews will be recorded for later verbatim transcription into a typed word processing document. Recordings will remain confidential, for access only by the researcher. Every effort will be made to protect the privacy and confidentiality of participants and identifying data will not be made available to anyone other than the researcher. Following transcription, recordings will be destroyed. Participants are able to request a copy of their transcribed interview. Should a participant remove consent after the data collection process has occurred, and before data has been combined for the purposes of analysis, any data collected from that participant will be withdrawn from the study as requested. Access to transcripts will be limited to the researcher and the two academic supervisors of the research project, Dr. Janette Curtis, School of Nursing, Midwifery and Indigenous Health and Dr. Peter Caputi, School of Psychology, University of Wollongong.

Should material of a personally distressing nature arise during the interview, provision has been made for a debriefing session to be available on request to assist in reducing symptoms of distress with follow-up counselling if required. While it is not an anticipated outcome of the interview process, the researcher, as a registered nurse, has a professional obligation to notify relevant authorities should material be disclosed during an interview that falls within mandatory reporting guidelines, most notably, for children at risk or threats for harm towards others.

If you are interested in participating, you will be required to complete an expression of interest in participating (attachment 1) and a consent form (attachment 2). Participation remains voluntary throughout the process and consent can be withdrawn prior to data being de-identified within the analysis phase, without the participant suffering any disadvantage.

Should participants have any concerns or complaints regarding the way in which the research is or has been conducted, please contact the Secretary of the University of Wollongong Human Research Ethics Committee on (02) 4221 4457.

Sue Liersch ☎ 4221 3472; or 🖳 sliersch@uow.edu.au

Appendix 4: Research information page

**Invitation to participate
and information for research to explore
'the meaning of *resilience* for people who experience schizophrenia'**

You have been sent this invitation to participate and research information pack by the Community Mental Health service who has been asked by a research team to forward this information to people who live with schizophrenia. Your identity has not been disclosed to anyone outside of the Community Mental Health Team in this process.

Participation is voluntary and potential participants are free to refuse to participate, or having consented, to withdraw their consent without that refusal or withdrawal affecting their treatment, care, studies or relationship with the health service or University of Wollongong.

The aim of this research is to identify the meaning of resilience for people who experience schizophrenia. Resilience has been identified in literature as an important personal quality contributing to a positive outcome for a person who experiences adversity and has been studied in many areas of life, including; adolescent development, education and recovery from illness. Results of this study would contribute knowledge about the meaning of resilience for people who experience schizophrenia.

The Researcher Sue Liersch, is a post-graduate student of the School of Nursing, Midwifery and Indigenous Health at the University of Wollongong. The research project is being supervised by Associate Professor Janette Curtis, School of Nursing, Midwifery and Indigenous Health and Dr. Peter Caputi, School of Psychology, University of Wollongong. The researcher also works as a Registered Nurse in a mental health setting for the Greater Southern Area Health Service who have given permission for this research to be conducted but are not involved in the research process or result other than to offer clients the opportunity to participate and provide a room for confidential research interviews. This research does not form part of the current clinical role of the researcher.

Participants are asked to attend a confidential interview and will be asked questions about their meaning of resilience. Interviews are expected to be around 60 minutes and will be tape-recorded to be later typed up as a transcript of interview.

The information you provide will contribute to strengthening knowledge on resilience and schizophrenia. Data will also be used for fulfilment of part of the requirements for the researcher to gain an educational qualification through writing a major thesis including the results of this research.

Participant's names will be coded and be known only to the researcher and names of participants will not be associated with any published research data. Tape-recordings will remain confidential, for access only by the researcher and will be destroyed after being typed up. Participants are able to request a copy of their transcribed interview. Access to interview transcripts will be limited to the researcher and the two academic supervisors of the research project, Associate Professor Janette Curtis and Dr. Peter Caputi. Interview transcripts will contain only the code for the participant and not the name of the participant. Transcripts will be stored in a locked cabinet at the University of Wollongong.

Should content of a personally distressing nature arise during the interview, provision has been made for a debriefing session to be available on request, through community mental health, to assist in reducing symptoms of distress with follow-up counselling if required.

If you would like to participate, please complete the attached consent form and return it in the envelope provided. If you do not wish to participate, you need not do anything further & can dispose of the research information.

Should you have any concerns or complaints regarding the way in which the research is or has been conducted, please contact the Secretary of the University of Wollongong Human Research Ethics Committee on (02) 4221 4457.

If you have any questions, please feel free to contact the researcher;

Sue Liersch ☎ 4221 3472 or ⌨ sliersch@uow.edu.au

Appendix 5: Participant consent form

RESEARCH PROJECT

'The meaning of resilience for people who experience schizophrenia'

<u>CONSENT FORM</u>

I have been given and have read information about the research project entitled 'the meaning of resilience for people who experience schizophrenia'. I understand that if I consent to participant in this project I will be asked to attend a confidential interview with the researcher of around 60 minutes duration during which time I will discuss what I perceive the meaning of resilience to be.

I understand the interview will be recorded, that the recording will be destroyed following successful transcription and that my identifying details will be kept confidential and my confidentiality maintained throughout the research process unless I request otherwise. I understand that I am able to request a copy of the completed transcript of my interview. I understand that data from my interview will be used only for the purposes of this research project and the associated major thesis and will not otherwise be used without my permission.

I understand that the researcher, as a registered nurse, has a professional obligation to notify relevant authorities should material be disclosed during an interview that falls within mandatory reporting guidelines, most notably, for children at risk or threats for harm towards others.

I understand that I am free to refuse to participate and I am free to withdraw from the research. If I withdraw after my interview has been conducted, any data collected from me will be withdrawn from the study up until such time as my data has been de-identified and combined with others' data in the analysis phase. My refusal to participate or withdrawal of consent will not affect my relationship in any way with the Greater Southern Area Health Service, the researcher or the University of Wollongong.

If I have any enquiries about this research, I can contact Sue Liersch by phone on 4221 3472 or email on sliersch@uow.edu.au or Dr. Peter Caputi or Dr. Janette Curtis on 4221 3555. If I have any concerns or complaints about the way the research is or has been conducted, I can contact the Secretary of the University of Wollongong Human Research Ethics Committee on 4221 4457.

By signing below, I am indicating my consent to participate in the research entitled 'the meaning of resilience for people who experience schizophrenia', conducted by Sue Liersch as it has been described to me in the information sheet. I understand the data collected from my participation will be used for a thesis and I consent for it to be used in that manner.

_____   _____

Signed   Date

_____   ☎_____

Name (please print)   Your phone no. for contact by
                                                                              researcher to arrange interview

Appendix 6: Draft study maps

(WORKING DOCUMENTS ONLY)

STUDY MAP – WHAT IS THE MEANING OF RESILIENCE FOR A PERSON WITH SCHIZOPHRENIA?

QUESTIONS
1) What are the positive aspects of schizophrenia and why is knowledge of them missing in the therapeutic milieu?
2) Why do clinicians demonstrate a pessimistic attitude towards the diagnosis of schizophrenia?
3) Is an optimistic outcome possible for schizophrenia?
4) What is an optimistic outcome for schizophrenia?
5) How is an optimistic outcome achieved?
6) How can this knowledge be used clinically to communicate the positive and optimistic aspects of the journey with schizophrenia?

LITERATURE REVIEW
Questions were answered through a synthesis of knowledge located across three fields of inquiry;
1) Schizophrenia
2) Recovery
3) Resilience

Findings of the literature review were;
1) There are positive aspects to having schizophrenia, such as being more creative however the 'diagnostic gaze' focussing on illness is incompatible with identifying positive aspects of schizophrenia.
2) Clinicians have been found to hold a pessimistic attitude towards the diagnosis of schizophrenia based on historical/traditional rather than evidential thinking.
3) An optimistic outcome is possible for people with schizophrenia.
4) The optimistic outcome for schizophrenia is linked with recovery. Successful outcomes in literature are linked with resilience.
5) Very little research has been done into how a successful outcome with schizophrenia is achieved or whether building resilience is possible for a person with schizophrenia, revealing a gap in knowledge.

GAP IN KNOWLEDGE – RESEARCH OPPORTUNITY

6) Define the meaning of resilience in the context of experiencing schizophrenia. Compare these definitions with those in resilience literature and to ascertain if people who have schizophrenia hold the same meaning. The purpose of this research would be to consider this knowledge could be used to develop an heuristic model to change attitudes in mental health clinical practice and thus provide a more optimistic and hopeful clinical experience and recovery process towards building of resilience for people with schizophrenia.

THEMES DEVELOPED THROUGH SYNTHESIS OF MEANING ACROSS LITERATURE TO EXPLAIN HOW SCHIZOPHRENIA, RECOVERY AND RESILIENCE FIT TOGETHER: '_THE SCHIZOPHRENIA EXPERIENCE_'

1) Schizophrenia is in control = having acute or chronic symptoms
2) The person is regaining control = being in remission or recovery
3) The person is in control = resiliently in control of schizophrenia symptoms and growing

RESEARCH QUESTION
What is the meaning of resilience for a person with schizophrenia?

STUDY
- 14 participants diagnosed with schizophrenia
- Living successfully with schizophrenia
- Semi-structured interviews, recorded and transcribed verbatim
- Thematic analysis conducted using Nvivo Data software to organise analysis into meaningful patterns and to identify themes and factors
- Ethical approval received from participating organisations

STUDY AIMS
1) Define resilience in the context of schizophrenia and compare with definitions in resilience literature.
2) Identify important factors related to living with schizophrenia.

AIM 1) FINDINGS - DEFINITION OF RESILIENCE IN THE CONTEXT OF SCHIZOPHRENIA
Analysis of definitions and narrative on resilience provided by participants resulted in the following synthesis of meaning;

Being resilient means adopting an attitude of striving to overcome the adversity caused by the experience of schizophrenia. The process of striving enables the person to learn about themselves, the effect of the schizophrenia illness on them, and how to manage it in the context of the life they want to live. Striving to overcome schizophrenia involves struggle, including repeated backwards steps and during this, the individual seeks out and uses supportive people and resources. Having then learned how to overcome and manage the challenges of schizophrenia the individual is then able to apply the same resilient attitude to engage in new challenges and experiences and to grow their life in ways unrelated to the illness. Through experiencing and overcoming the severe adversity of schizophrenia, the person has learned how to approach life resiliently.

Definitions of resilience provided by participants for resilience with schizophrenia were synchronistic with definitions of resilience in other contexts.

AIM 2) - FINDINGS (1)
Participant's descriptions of the experience of schizophrenia indicated a pathway of changing attitudes leading to conscious action to recover, followed by personal growth and development which is consistent with models describing recovery and the definition of resilience.

PATHWAY OF LIVING WITH SCHIZOPHRENIA

Feeling like a victim of schizophrenia
⇓
Stimulus for turning point
External pressure
Internalised change
⇓
Taking responsibility
⇓
Taking action
Taking control
Building knowledge
Try, try and try again
⇓
Maintaining gains
⇓
growing

AIM 2) - FINDINGS (2)
Participants articulated a range of factors associated with their journey through recovery to living with schizophrenia

Factors associated schizophrenia	No. of participants mentioning the factor (n=14)	No. of times mentioned across all interviews
1. Using medication	11	35
2. Having a supportive family	11	34
3. Being able to work	10	22
4. Having meaningful pursuits	9	21
5. Using professional help	9	21
6. Having other supportive people and groups	8	20
7. Having a healthy lifestyle	6	16
8. Managing stress	6	12

AIM 2) - FINDINGS (3)
Participants articulated a range of factors they found challenging and that made them vulnerable for re-emergence of symptoms of schizophrenia

Challenging factors associated with vulnerability	No. of participants mentioning the factor (n=14)	No. of times mentioned across all interviews
1. Medication challenges	7	13
2. Stress	5	13
3. Work stress	5	9
4. Family as a challenge	5	8
5. Difficult relationships	5	8
6. Health system barriers	4	9
7. Hormones for women	3	6
8. Stigma	3	5
9. Having a victim attitude	2	6
10. Obesity	2	4

STUDY MAP – WHAT IS THE MEANING OF RESILIENCE FOR PEOPLE WHO EXPERIENCE SCHIZOPHRENIA?

QUESTIONS PROMPTING LITERATURE REVIEW
1) Why clinicians demonstrate a pessimistic attitude towards the diagnosis of schizophrenia?
2) Is an optimistic outcome possible for schizophrenia?
3) What is an optimistic outcome for schizophrenia?
4) How is an optimistic outcome achieved?
5) How can this knowledge be used clinically to communicate the positive and optimistic aspects of the journey with schizophrenia to people who have been diagnosed with it?

↓

LITERATURE REVIEW
Addressing the questions required a journey of progressive reading through several different fields of inquiry;
1) Clinically/medically generated Schizophrenia literature
2) Consumer experience literature
3) Psychological recovery literature
4) Developmental and psychopathological resilience literature

Main findings of the literature review;
1) Traditionally, clinicians have adopted a pessimistic attitude towards the diagnosis of schizophrenia and also for the prognosis of people diagnosed with it, despite evidence for a good outcome for more than half of the people diagnosed with it
2) Creation of a recovery oriented service delivery paradigm, within which clinicians work to build the resilience of consumers has been mandated as the remedy for entrenched clinical pessimism and to create services which work to improve outcomes, rather than hinder them.
3) While much research is underway to support the implementation of recovery oriented services, little to no research has occurred for building resilience in the context of schizophrenia. This presents a gap in knowledge that is important for engaging with consumers for a positive and optimistic therapeutic journey with schizophrenia in which resilience is built.

↓

GAP IN KNOWLEDGE – RESEARCH OPPORTUNITY

6) A research project was developed to address the gap and to understand and describe the meaning of resilience according to people who live with schizophrenia so that building resilience within the therapeutic relationship may be better understood.

RESEARCH QUESTION
What is the meaning of resilience for people who experience schizophrenia?

↓

STUDY
- Ethical approval received from participating organisations
- Consent received from participants
- Interviewed 14 participants diagnosed with schizophrenia
- Semi-structured interviews, recorded and transcribed verbatim to produce interview transcripts
- Van Kaam's 12 step Psychophenomenological method used to analyse interview transcripts.

↓

STUDY AIMS
1) Describe the meaning of resilience for people who experience schizophrenia.

FINDING 1: – INTERPRETATION OF THE MEANING OF RESILIENCE FOR PEOPLE WHO EXPERIENCE SCHIZOPHRENIA

Resilience means adopting an attitude of striving to overcome the severe adversity caused by the experience of schizophrenia. The process of striving enables the person to learn about themselves, the effect of the schizophrenia illness on them, and how to manage it in the context of the life they want to live. Striving to overcome schizophrenia involves struggle, including repeated backwards steps and during this, the person seeks out and uses supportive people and resources. The process of seeking out and using support also comes with challenges and it is in competently overcoming these, in the quest for improvement that the person builds resilience. Resilience is then be used to seek out and engage in new challenges and experiences and to grow life in ways unrelated to just living to manage the illness. Through experiencing and overcoming the severe adversity of schizophrenia, the person has built the ability to approach life resiliently.

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FINDING 2: Participants discussed their experiences of schizophrenia. Many challenges occurred and particular decisions were made and actions are taken that were ascribed to being able to cope with and eventually overcome the challenges brought by schizophrenia. The meaning of resilience is found in the process of striving to overcome adversity. *A pathway was interpreted and is shown below, for the way in which challenges occurred, decisions were taken and actions were carried out that contributed to the meaning of resilience;*

A PATHWAY FOR THE MEANING OF RESILIENCE WHILE EXPERIENCING SCHIZOPHRENIA

Feeling like a victim of schizophrenia
Feeling pressure from others
⇓
Had an awakening/came to realise
and experienced a turning point
⇓
Took responsibility for recovering
⇓
Took control of my situation
Took action to recover
Didn't see it as failure, kept trying
Learned about self and illness
⇓
Made and maintained gains
⇓
Felt in control of life and Schizophrenia
⇓
Growing life in ways unrelated to the illness

FINDING 4 : *Living with schizophrenia involves many challenges and it is in competently overcoming these, in the quest for improvement that the person builds resilience. The relationship between schizophrenia and resilience is symbiotic. The protective aspects of the experience are important for the person's recovery and yet those very same protective resources can also contain difficult, challenging and risky aspects which when overcome, contribute to building resilience.*

1. Family and friends support me but they can also be unhelpful. Difficult relationships need to be managed.
2. Using medication is a choice and it comes with major challenges; seek to understand them.
3. Working is important for self-esteem but also involves stress that must be coped with.
4. Community connection brings a sense of belonging - find an outlet, hobby or exercise and also try to understand stigma.
5. Using professionals and support groups teaches coping, however the negative effects of health services also need to be coped with.
6. Feeling stress is normal and is not always related to the illness, learn to handle it.
7. Eat well, sleep well, behave well –believe that it's unhealthy to be overweight.
8. Practice acceptance; be willing, not wilful.
9. Don't take on the victim role- be willing to take responsibility.
10. To see it as failure is wrong - be proud of success.
11. Trust others and care for the people who care for you.

FINDING 3: Within the journey defined in Finding 2, changes in attitudes about the self in relation to schizophrenia were described by participants. These have been interpreted and presented below as three distinct attitudes;

LOST SELF	SELF STRUGGLING, STRIVING	GROWING SELF ANEW
Felt Like a victim of schizophrenia Felt pressure from others	Experienced an internal change or a turning point Took responsibility Took control Took action Didn't see it as failure, kept trying Learned about self and illness	Made and maintained gains Felt in control of life and schizophrenia Growing in ways unrelated to illness
SEE SELF AS A VICTIM OF SCHIZOPHRENIA	SEE SELF AS STRUGGLING AND STRIVING TO LIVE WITH SCHIZOPHRENIA	SEE SELF AS LIVING A BETTER LIFE AND BEING ABLE TO CONTROL SCHIZOPHRENIA