# Resilience, Psychosis and Childhood Trauma

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#### Abstract

This research investigates resilience. It examines the influence of childhood trauma and/or adversity on resilience in adults diagnosed with a psychotic illness. In the research I grounded resilience in the lived experience of psychosis and childhood trauma and/or adversity and framed these topics within a health, psychological and social perspective.

This research comprises two studies. I utilise quantitative and qualitative research data sets in a mixed-method research design. I drew the quantitative study data from the Survey of High Impact Psychosis research project conducted in the northern region of Adelaide, South Australia in 2010. I combined this quantitative study with a qualitative study based on data from additional interviews involving a smaller participant group sourced from the SHIP research project. I selected interview participants for the qualitative study because they identified as having experienced childhood trauma and/or adversity.

The mixed-method research design provides the capacity to identify the prevalence of childhood trauma and/or adversity within a psychosis cohort. It allows for the examination of the effects of childhood trauma and/or adversity and psychosis on the development and manifestation of resilience. I also consider the influence of a psychotic illness on health, and economic and social functioning. The qualitative phase of the research examined individual interpretations of the experience(s) of childhood trauma and/or adversity, psychosis and resilience. I analysed this qualitative data thematically and identified some of the common understandings of not only the construct of resilience, but also the lived experience of psychosis.

This research establishes that resilience has a crucial role in optimising social and health functioning. It identified how childhood trauma and/or adversity is a contributor to the

development of resilience in people with psychosis. In addition, the research demonstrates that resilience is fundamental to long-term recovery from psychosis. I also consider the implications of the research findings for enhancing the effectiveness of clinical mental health approaches to psychosis treatment. A more intentional focus on the development of resilience in clinical mental health practice emerged as one of the primary recommendations from the research.

#### **Declaration**

I, Shaun Sweeney, certify that this work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution, and, to the best of my knowledge and belief, it contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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Shaun Sweeney

Date: 16th June 2015

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## The Survey of High Impact Psychosis

This PhD is based on data collected from the 2010 Australian National Survey of High Impact Psychosis. The members of the Survey of High Impact Psychosis Study Group are: V. Morgan (National Project Director), A. Jablensky (Chief Scientific Advisor), A. Waterreus (National Project Coordinator), R. Bush, V. Carr, D. Castle, M. Cohen, C. Galletly, C. Harvey, B. Hocking, A. Mackinnon, P. McGorry, J. McGrath, A. Neil, S. Saw and H. Stain. I would like to thank these national directors for not only providing me with the opportunity to participate in collecting this data, but also the chance to use this data in a PhD research project. I would also like to acknowledge the hundreds of mental health professionals who participated in the preparation and conduct of the 2010 Australian

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# **List of Publications and Conference Presentations**

# **Publication List**

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- Sweeney, S., Zannettino, L., Air, T., Gallelty, C. (2014). 'Psychosis,
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- Shah, S., Mackinnon, A., Galletly, C., Carr, V., McGrath, J., Stain, H., Castle, D.,
   Harvey, C., Sweeney S., Morgana V. (2014). 'Prevalence and impact of childhood abuse in people with a psychotic illness: Data from the second Australian national survey of psychosis'. *Schizophrenia Research* 159 (2014): 20–26.

## **List of Conference Presentations Based on this Thesis**

 'The Survey of High Impact Psychosis: A national research project from a South Australian perspective'.

Shaun Sweeney, Prof Cherrie Galletly, Dr Lana Zannettino
TheMHS Conference. Adelaide, South Australia, 6–9 September 2011.

• 'Trauma in childhood and the outcomes for psychosis cohorts'.

Shaun Sweeney, Prof Cherrie Galletly, Dr Lana Zannettino

The 7<sup>th</sup> Annual World Conference on the Promotion of Mental Health and
Behavioural Disorders. Perth, Western Australia, 17–19 October 2012.

• 'Resilience, childhood trauma and the outcomes for psychosis populations'.

Shaun Sweeney

Statewide Mental Health Workers' Seminar. Glenside Hospital Campus. Adelaide, South Australia, 6 December 2013.

'Resilience, psychosis and childhood trauma'.

Shaun Sweeney.

School of Medicine Research Highlights. Adelaide, South Australia, 9 September 2014.

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#### **Preamble**

To the reader,

This is a 'hybrid thesis' comprising a traditional research thesis format including two additional journal articles. An advocacy position for a stronger clinical focus on resilience in mental health practice is evident in this research, a position that emerged through the experience of conducting this research. Furthermore, in my work as a mental health clinician with broad mental health experience I have observed firsthand how psychosis can affect a person's physical and psychological health, employment opportunities, educational outcomes and their participation in community life. Despite these obstacles, many people with a psychotic illness maintain resilience and optimism about their futures. However, there is still much to be done to improve mental health praxis to ensure that people with a psychotic illness can live meaningful and contributing lives as members of their communities.

# Chapter 1

#### Introduction

#### 1.1 Overview

This research investigates resilience. It explores how it can influence the health, and psychological and social functioning of people with a psychotic illness. The research also investigates the effects of childhood trauma and/or adversity (CTA) and its links to resilience in a psychosis population. The potential of resilience to enhance illness recovery from psychosis is also explored. In this research I utilise data collected from two sources: the Survey of High Impact Psychosis (SHIP) project (see Morgan, et al. 2012) as well as qualitative interview data collected specifically for this PhD research.

Resilience and its relationship to health and psychosocial functioning has been widely investigated in the domains of psychology, education and health over the last four decades. However, less attention has been given to the investigation of resilience in populations affected by complex health and social issues. In this PhD research I seek to build on current knowledge about the manifestation of resilience. In particular, I investigate resilience in a psychosis population living in a disadvantaged community in the northern region of Adelaide, South Australia. The research is informed by a large body of research in the field of mental health. This has consistently demonstrated a reciprocal relationship between psychosis and poor health, and social and economic disadvantage (Dohrenwend, Levav et al. 1992, Dixon, Postrado et al. 1999, Saraceno, Levav et al. 2005, Ramsay, Stewart et al. 2012).

I describe the community socioeconomic context in which the research population live and how poverty and social marginalisation can affect people with psychosis. I also investigate how psychosis influences a range of health and socioeconomic functioning. I analyse the complex interactions between social disadvantage, health and psychosocial outcomes, and the role of resilience in influencing these outcomes. Moreover, I examine how resilience can be shaped by the experience(s) of CTA and how this experience(s) can influence the recovery from psychosis. In summary this PhD research investigates resilience in the lives of people with psychosis and how CTA, as well as health, and psychological and socioeconomic status defines and mediates resilience in people's lives.

# 1.2 Research Origin

The ideas and questions that underpin this research arose while I was undertaking a role as the South Australian Coordinator for the Survey of High Impact Psychosis (SHIP) research project. SHIP is a national research project that began data collection in 2009-2010. The northern region of Adelaide in South Australia was one of seven Australian catchment areas for the SHIP study. The SHIP researchers sought to examine the domains of emotional, physical and social functioning within the context of the lifetime experience of psychosis. As the SHIP research coordinator in South Australia, my initial analysis of the data in 2010 indicated that the prevalence of CTA in the participant group appeared to be quite high. This initial finding prompted my interest in exploring the relationship between CTA and psychosis and, more specifically, the role that resilience may have in influencing the recovery from psychosis.

My previous clinical mental health work history made me acutely aware of the complexity of the lived experience of psychotic illness. In this work I had observed that, despite severe health, psychological and social effects of psychosis, some individuals appeared to demonstrate some of the traits of resilience. This was evident in how they managed their illness and coped with the challenges of their daily lives. However, I was also aware that research in the field had found that CTA could have a negative psychological and social

effect in adulthood, including the potential development of psychosis. The high prevalence of CTA in the South Australian SHIP cohort therefore raised the following questions:

- 1. How statistically significant was the prevalence of CTA in this cohort?
- 2. Were there differences in the health, psychosocial and socioeconomic outcomes between individuals with the experience(s) of CTA and those without?
- 3. How did CTA impact on how individuals coped with and managed the challenges of the lived experience of psychosis?
- 4. Did the experience(s) of CTA impair or enhance resilience and psychosocial functioning?

These questions led to the primary focus of the research: the investigation of the significance of CTA in the context of resilience for people with a psychotic illness. Given my previous work history in the field, I was also interested in the potential clinical mental health practice implications of the research findings. The experience of coordinating the SHIP project in South Australia had led me to explore some of the clinical practice paradigms that underlie mental health service delivery. Moreover, in my own clinical mental health training and experience, CTA and its potential impact on the development of resilience were not viewed as practice considerations and/or imperatives. Consequently, I began to consider the possibility that a lack of acknowledgement of CTA may diminish the effectiveness of clinical mental health practice. Therefore, investigating whether and how CTA was linked to the development of resilience in people with psychosis became an important aspect of encouraging a broader discussion about the efficacy of current clinical practices with this population.

As I have stated, I conducted this PhD research in a socially and economically diverse region in South Australia characterised by comparatively high levels of socioeconomic disadvantage and poverty. Social and economic isolation is reflected in poor physical health, social segregation, and a reduction in participation in social, educational and employment opportunities (Weich, Lewis et al. 2001, Hjern, Wicks et al. 2004, Harper 2011). I will consider these poor health and social outcomes in the context of how they influence illness recovery and define the social and primary health care focus of this research. Furthermore, my own clinical mental health experience had predominantly been in services located in disadvantaged communities. Consequently I had some awareness of how low socioeconomic status can exacerbate the inherent challenges of living with a mental illness. However, I had also observed that, despite these complex challenges, some people with psychosis appear to display considerable resilience. This observation led to the conviction that an investigation of resilience in psychosis populations needs to consider how the social and economic circumstances of the research population also influenced their health and psychosocial outcomes. Central to this question was whether and how resilience may enable individuals to manage their complex illness and its effects, such as poor health, economic hardship and social isolation.

## 1.3 Research Questions

Following an initial analysis of the data I expected that mental illness as well as other comorbid illnesses within the SHIP cohort would indicate that psychosis, anxiety, depression, substance abuse and poverty would be more severe in the CTA-positive cohort. Furthermore, I anticipated that people with the experience(s) of CTA might indicate lower socioeconomic functioning and higher rates of social dysfunction compared with the non-CTA cohort. These assumptions were supported by evidence from an initial literature search that indicated poorer socioeconomic, health and psychosocial functioning in people

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<sup>&</sup>lt;sup>1</sup> Census data (2006) for the South Australian SHIP catchment area was extracted by the ABS

with the experience of CTA. However, the body of research from which this evidence emerged predominantly considered CTA within general population samples. The evidence indicating poorer outcomes for people with both CTA and psychosis was not replicated in the findings from this PhD research. As this challenged my initial assumptions, it led to the following questions that I consequently refined into the PhD research aims as described in section 1.2:

- 1. Why is it that some individual participants from the SHIP cohort appear to flourish despite their experience(s) of CTA while others are less successful in overcoming the ongoing emotional, psychological and social challenges created by psychosis?
- 2. How does resilience affect functioning?
- 3. Does CTA influence the development of resilience? And, if so, how?
- 4. How does resilience affect people's capacity to manage the psychological, social, medical and economic challenges of living with psychosis?
- 5. What are the implications of answers to these questions for mental health policy, systems and service delivery?

# 1.4 Topic Overview

Resilience has commonly been defined in terms of the interrelationship between the health, psychological and social factors important to the development of healthy psychological and social functioning (Rutter, 2007). However, the construct has had several meanings that have evolved over time. For example, resilience has been described as a personal quality that can enable a person to flourish when faced with adversity (Connor & Davidson, 2003). It has also been defined as the psychological ability to bounce back from adversity (Wagnild, 2003). However, there is now a general consensus in the field that resilience is a pattern of functioning indicative of positive psychological adaptation in the context of risk and/or adversity. Fundamental to this notion of resilience are two central

conditions: (a) exposure to significant risk, and (b) evidence of positive adaptation and growth despite serious threats to psychological development (Ong, Bergeman et al. 2009).

However, the notion that people with psychosis may exhibit resilience in ways that could influence their illness self-management and recovery appears to have been overlooked in research and clinical mental health practice. Therefore, the role of resilience in developing the capacity of a person with psychosis to manage the complex social, health and psychological challenges associated with the illness is somewhat unclear. This is despite an increasing emphasis in clinical mental health, psychological and social work practice on a strengths-based approach to mental health intervention and support that underlies recovery-based service mandates (Brun & Rapp, 2001).

The understanding that CTA experience(s) can influence adult mental and physical health is now generally accepted in psychoanalytic theory. The relationship between CTA and the development of mental illness, such as psychosis, has been confirmed in a number of significant studies (Read, Fink et al. 2008). However, while these links have been established (Larkin & Read, 2008), there is less clarity about the relationships between CTA, mental illness and important psychological competencies such as resilience. Additionally, less attention has been paid to the effects of CTA on the development of resilience in people with a psychotic illness. In this PhD research I therefore aimed to provide deeper insights into the prevalence, presentation and psychological influence of CTA in a regionally representative psychosis population. In focusing on psychosis, CTA and resilience, I aimed to address existing knowledge gaps about these combined and interacting domains in current mental health research and clinical mental health practice settings. I did this within a South Australian context and with due consideration to the

economic, service and policy complexities of delivering a mental health service in this region.

#### 1.5 Research Aims

As I have discussed, the purpose of this research was to investigate the significance and prevalence of resilience in people with a psychotic illness who have a history of CTA. In so doing, I aimed to remove some of the ambiguity surrounding the notion of resilience, particularly in the context of psychosis. I sought to develop an evidence base in relation to how resilience is understood and how it is manifest in the lives of people with a psychotic illness *and* a history of CTA. Therefore, the aim of this research was to:

1. Examine whether and how CTA influences resilience for people with psychosis.

In this research I intended to:

- 1. quantitatively examine psychosis and CTA in the context of health and social outcomes within a regionally representative participant sample. I aimed to utilise quantitative data from the South Australian SHIP research project to:
  - a. investigate the relationship between psychosis, health, and economic and social functioning;
  - b. investigate the relationship between CTA and health, and economic and social functioning.
- 2. qualitatively study resilience and how it is manifest in a CTA-positive sample of the South Australian SHIP cohort. I aimed to use this qualitative study to:

- a. examine participants' personal perspectives of their experience(s) of
   CTA including whether and/or how CTA influences resilience;
- b. investigate the significance of resilience, including whether and/or how it impacts on illness recovery and psychosocial functioning;
- c. examine the potential role of resilience in clinical mental health settings.

#### 1.6 Health and Social Context

As I have previously described, the research population was drawn from the SHIP research project conducted in a South Australian region characterised by comparatively high levels of poverty and socioeconomic disadvantage. Studies in the field of mental health have established that people with a mental illness often reside in communities experiencing similar levels of socioeconomic disadvantage (Saraceno & Barbui, 1997, Lund, De Silva et al. 2011). Research in the field has also consistently confirmed the relationships between mental illness, poverty, and poor physical and social health (Mueser & McGurk, 2004, Steel, Marzillier et al. 2009). Furthermore, research has also established that social context can itself be a contributing factor in the aetiology of mental illness (March, Hatch et al. 2008). Thus, I utilised Australian Bureau of Statistics (ABS) data for South Australia to highlight the prevalence of psychosis in the research cohort. I utilised this ABS data drawn from the 2006 ABS census to clarify how psychosis is manifest in the community and to explore some of the broad health and social outcomes of the SHIP research population. My analysis of data from the SHIP research project provided detailed information on the health and social profile of the research population. Emerging from the analysis of these two data sources was a description of how social and economic factors can shape the health and social functioning of individuals. This has provided an insight into how these factors can exacerbate the challenges of living with psychosis. Therefore, whether and/or how resilience can enhance the capacity of individuals to manage these complexities emerged as a central question for this investigation. This question was framed within the health and social context of the research population described above.

## 1.7 Research Method and Design

## 1.7.1 Research Methodology

I utilised a mixed-method approach in this research. I analysed quantitative data from the South Australian SHIP research project and combined it with supplementary qualitative data. I collected this qualitative data from face-to-face interviews with participants who specifically identified the experience(s) of CTA from the South Australian SHIP sample.

The purpose of quantitatively analysing the South Australian SHIP data was to provide a range of information relating to the health, economic and social domains of the research population. This identified the context in which the lived experience of psychosis occurred. The supplementary qualitative data allowed for the exploration of social and psychological domains not addressed in the SHIP data set; namely, resilience in the context of CTA. I analysed this qualitative data thematically to explore how CTA may influence the development of a participant's resilience, their psychosocial condition, and socioeconomic status. This included exploring participants' understandings of their recovery from psychosis and the role that resilience may have had in this recovery.

These combined data sets underpin the findings and contributions of this research. They provide the scope to discuss the implications of resilience and help identify a range of recommendations for clinical mental health service provision. These recommendations are related to the provision of mental health services for psychosis populations but may also be applicable to other health cohorts.

## 1.7.2 Research Design

Given the combined use of both quantitative and qualitative data sets and the mixed-method research process, in this research I utilise a two-tiered study design. Figure 1.1 illustrates how the research typology integrated the SHIP data and the qualitative interview data (for a more detailed description of the research methodology, please see Chapter 3). I analyse each data set in greater detail in Chapter 4 (Study One) and Chapter 6 (Study Two).

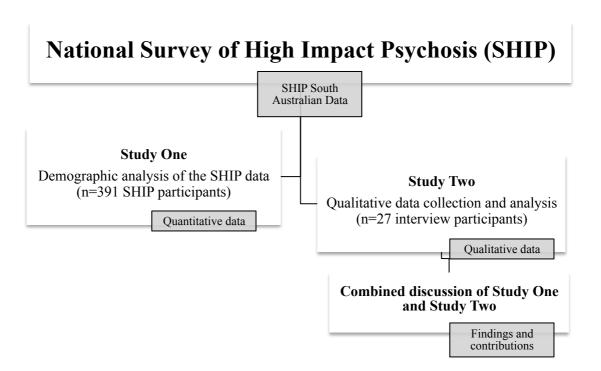


Figure 1.1: Research Typology

## 1.8 The Use of Terminology

I use some terminology interchangeably in the text of this PhD to suit the context of the topic(s) under discussion. Here I will provide a brief description of resilience, psychosis, CTA, psychosocial functioning and illness recovery in order to establish consistency throughout the document. I discuss the major terms resilience, CTA and psychosis in detail in Chapter 2, including the definitions of the terms as they pertain to this PhD research.

I use the term 'resilience' interchangeably to describe the capacity to recover emotionally and psychologically or 'bounce back' from adversity.

I use the phrase 'childhood trauma and/or adversity' or CTA to describe the commonly accepted understandings of trauma as experienced during childhood and/or adolescence. This includes the experience(s) of abuse, neglect, family breakdown, tragedy, and other types of challenging and/or adverse psychological or physical events. I also use the terms 'trauma' and 'trauma and/or adversity' interchangeably to suit the context of the discussion. For example, I use 'trauma' to describe the experience(s) of trauma, while I use 'CTA' specifically to describe the experience of trauma and/or adversity during the years 0 to 18. In the SHIP research, CTA was rated using a self-reported item about childhood trauma in the childhood adversity module of the SHIP interview schedule. In Australia child abuse and protection is a state and territory government responsibility, and all states follow a national framework of guidelines for defining CTA, such as child abuse or neglect (Australian Institue of Health and Welfare, 2012).

In the context of this PhD research, the term 'recovery' refers to an individual with a mental illness having a safe, dignified, personally meaningful and gratifying life while also seeking to manage a complex mental illness. This perspective of 'recovery' differs from other common understandings of the concept. That is, illness recovery is often viewed as 'being cured' from an injury or physical illness. Recovery in the context of mental illness relates specifically to the acknowledgement of mental illness as a lifelong psychological condition that varies in its day-to-day presentation, with symptomology that presents numerous health, psychological, social and economic challenges for the individual. Recovery from mental illness refers to living the best possible life with the condition

despite the lifelong challenges this may present. The notion of recovery from mental illness emphasises a person's right to self-determination and their engagement in typical life pursuits such as education, employment, sexuality, friendships, spirituality and community membership. The concept of recovery is consistent with the person's own goals, values and preferences (Davidson & Roe, 2007), and I use it throughout this thesis to describe how one manages and flourishes while living with a lifelong illness.

The terminology of psychosis or psychotic illness typically characterises some of the profound changes in personality and impaired functioning inherent in schizophrenia. A distorted or non-existent sense of objective reality typifies the experiences of those with psychosis. People with psychosis can also experience a diminished sense of reality; that is, they are unable to distinguish personal subjective experiences from the reality of their external world. The terminology of psychosis can also describe people's experience of hallucinations and/or delusions, which can lead them to behave and communicate in an inappropriate and incoherent fashion.

The terms 'psychosocial' and 'psychosocial functioning' relate to an individual's psychological development in, and their interactions with, their social environments. The psychological and social functioning of a person can play a significant role as they manage the challenges in their lives such as mental or physical illness.

# 1.9 Combined Thesis and Journal Papers

The design and content of this PhD research has provided scope to produce a traditional thesis combined with two journal papers related to the research topics. These two papers have been submitted to peer-reviewed journals and are awaiting decisions to publish.

## 1.10 Chapter Overview

# 1.10.1 Chapter 1

Chapter 1 has outlined the background, aims and objectives of this research. I have provided an account of my research and clinical practice experiences that led to my interest in the research topic. I described the process of formulating and refining the questions into specific aims and introduced the research method and design. I described a rationale for the health and social perspective that frames the research and clarified the terminology applied throughout the research.

# 1.10.2 Chapter 2

Chapter 2 conceptualises the research topics under investigation. I present a review and evaluation of the literature relating to the research topics introduced in Chapter 1. This includes examining the relevant research, theories and perspectives about resilience, CTA and psychosis. The chapter has a particular focus on resilience theory and research and I also examine the links between resilience, CTA and psychosis. I highlight research that establishes the relationship between psychosis and social disadvantage as a precursor for the discussion of Study One in Chapter 4.

# 1.10.3 Chapter 3

Chapter 3 provides a detailed account of my research methodology. This includes the rationale underpinning the research method. I describe the processes undertaken and the challenges that arose during the conduct of the research in relation to the sourcing of participants, conducting interviews and the data analysis. I discuss my role as the researcher, including a reflexive analysis of how the researcher is positioned in the process. I also discuss the ethical and moral issues that arose during the conduct of the research.

## 1.10.4 Chapter 4

Chapter 4 details the quantitative analysis of the South Australian SHIP data, focusing on both the CTA and non-CTA groups. I present a range of health, social, economic, vocational and illness data for the two groups. I highlight differences and similarities between the two cohorts. In addition, I provide demographic information about the SHIP catchment sourced from the Australian Bureau of Statistics. This creates a detailed picture of the social and economic context in which the research participants live. The chapter demonstrates the range of factors that shape the health and social functioning of the research group.

# 1.10.5 Chapter 5

This chapter contains the published paper: 'The physical and psychological manifestation of childhood trauma and /or adversity in people with psychosis'. This paper draws on data from the SHIP project and is an additional quantitative analysis of the South Australian SHIP data. The paper specifically examines the self-reporting of physical illness in adults with a history of CTA.

# 1.10.6 Chapter 6

This chapter describes Study Two. I provide a detailed qualitative analysis of the face-to-face interview data to explore participants' personal experiences(s), perceptions and insights about psychosis and CTA. As such, this chapter provides a deeper insight into the significance of CTA, psychosis and resilience in the lives of people with psychosis. It is augmented by the quantitative information from Study One relating to the health and social outcomes of the research population presented in Chapter 4. Both studies provide a comprehensive account of how individuals with psychosis and CTA live challenging lives exacerbated by the effects of social disadvantage. This chapter also illustrates that some people with psychosis display resilience in order to manage these challenges.

## 1.10.7 Chapter 7

Chapter 7 contains the published paper: 'Psychosis, health, and social disadvantage in South Australia: Findings from the Second Australian National Survey of Psychosis'. This paper focuses on the quantitative analysis of the South Australian SHIP, specifically emphasising the links between psychotic illness, socioeconomic disadvantage and physical health. It examines the effect of psychosis on poverty, physical health, employment and socioeconomic participation. Referring to the South Australian SHIP cohort, the paper highlights some of the links between psychosis, poor health, social disadvantage, substance use and the corresponding high levels of socioeconomic isolation of psychosis populations. It includes recommendations for changes to current mental health practice and future research possibilities that enhance understanding in this area of mental health service delivery.

# 1.10.8 Chapter 8

Chapter 8 discusses the findings and the contributions of the research, including their implications for clinical mental health service provision. I examine the efficacy of current mental health policies, treatment praxis and service delivery and identify future research possibilities in this field. This chapter integrates the findings of the quantitative analysis of the South Australian SHIP data from Study One with the findings of the qualitative analysis of the interview data from Study Two in order to generate a range of praxis-related clinical mental health recommendations.

# 1.10.9 Chapter 9

Chapter 9 provides a concluding discussion based on the outcomes of the research process. This chapter summarises the entirety of the PhD research, and establishes links between the initial questions raised in the introduction and the outcomes of the research. I also analyse the strengths and limitations of the research process.

# 1.11 Conclusion

This introductory chapter has presented the rationale, aims and objectives of the research. I have also clarified the terminology used throughout the research. I presented an overview of the concept of resilience, the SHIP research project, and the health and social context of the topics under investigation. In the following chapters I explore resilience, CTA, psychosis and recovery further. The next chapter reviews the literature in the field and establishes the empirical and theoretical framework for understanding these complex health and social topics.

### Chapter 2

### Literature Review

### 2.1 Introduction

This chapter outlines the research evidence and theoretical understandings that underpin the fields of psychosis, CTA and resilience. I focus on the body of evidence that links CTA and resilience in people with a mental illness. I explore the concept of illness recovery within mental health practice. I discuss the implications of resilience for recovery practice and clinical mental health service provision.

### 2.1.1 Literature Search

The literature in the health and psychological domains of psychosis, CTA and resilience is substantial and diverse. Reviewing this complex field creates challenges for any researcher. Firstly, the diverse medical and social perspectives characteristic of each of the above fields has to be negotiated, synthesised and applied to the research topic. Secondly, an initial search strategy has to be identified. Thirdly, relevant material relating to the research topics needs to be extracted from the literature in a way that ensures consistency and objectivity. Finally the literature needs to be integrated into a concise and accessible format that is rich in detail (Lilford, Richardson et al. 2001). To address these challenges I adopted a method for conducting literature reviews proposed by Lilford, Richardson et al. (2001) for this study. Below I provide further details of how I applied this method.

An extensive and growing field of research exists in the fields of psychosis, CTA and resilience. To assist in the search of the extensive databases in these respective domains, I conducted a search of the major bibliographic databases. The purpose of this strategy was to avoid searching too extensively (i.e. by searching contrasting databases and information sources). My further aim was to locate journal articles that examined both conceptual

understandings and definitions of the research topics including epistemology, measurements, critiques and related topics. The databases I searched were Scopus, Psyc-INFO, Academic Search Premier, PubMed, Academic OneFile and Science Direct.

I deliberately selected broad search terms such as those below to identify the research topics. I applied these to each database.

- resilience AND psychosis;
- childhood trauma and/or adversity AND resilience;
- psychosis AND CTA;
- recovery practice AND mental health;
- post-traumatic stress disorder (PTSD) AND mental illness;
- post-traumatic growth (PTG) AND psychosis.

I reviewed the titles and abstracts of all identified papers to assess their relevance. I electronically retrieved and reviewed all potentially relevant papers. I subsequently scrutinised each paper and extracted information that met the inclusion criteria below:

- Resilience, including:
  - o resilience;
  - the psychological, biological and social factors associated with resilience;
  - o resilience in educational contexts;
  - o the developmental contexts of resilience;
  - o assessment(s) of resilience.
- Childhood trauma and adversity, including:
  - o the prevalence of CTA;

- o the health implications of CTA;
- o the psychological implications of CTA;
- the social implications of CTA;
- o the influence of CTA on psychosocial functioning.

## • Psychosis, including:

- the development of psychosis;
- o the symptoms related to psychotic illness;
- o the prevalence of psychosis;
- o psychosis, poverty and social disadvantage.
- Post-traumatic stress disorder and post-traumatic growth, including:
  - o the prevalence of mental illness following traumatic stress;
  - o the symptoms of post-traumatic stress disorder;
  - o post-traumatic growth AND mental illness recovery.

I have included a short review of the literature relevant to each chapter topic in several chapters of this thesis to highlight how the literature contextualised specific topics.

# 2.1.2 The Conceptualisation and Terminology of Resilience

The field of resilience is characterised by some conceptual ambiguity and differences in the use of terminology. These differences appear to be related to the context in which resilience is discussed or applied. For example, the concept of resilience in a childhood educational context differs from how resilience is used from a mental health perspective. This has implications for the methods used to identify resilience and its application in mental health treatment, counselling and clinical support for people with a mental illness. However, despite some differences and contradictions in the field, a shared understanding of the construct has begun to emerge. Furthermore, in discussing conceptual differences and consequent confusion in the use of terminology in the resilience field, a number of

writers have suggested there is a need to be cautious about how the term is used. For example, Luthar, Cicchetti and Becker (2000) assert that the term 'resilience' should be used rather than 'resiliency', as the latter implies resilience is a 'distinct psychological characteristic' (Luthar, Cicchetti & Becker, 2000, p.546). Similarly Masten (1994) cautions against the use of the term 'resiliency', suggesting it implies that individuals do not have 'what it takes' to overcome an experience of CTA and other trauma.

# 2.1.3 The Conceptualisation and Terminology of Illness Recovery

As Bonanno (2004) suggests, in order to better understand the role of resilience in enhancing recovery from mental illness, clarity needs to be established about the process of 'recovery' or 'recovering'. Recovery is best described as a: 'model, philosophy, approach, a paradigm, a movement or vision' about getting well and maintaining 'wellness' from illness (Roberts & Wolfson, 2006). However, in both the domains of research and mental health practice the term itself has become ubiquitous and is often used in inconsistent and interchangeable ways (Cleary & Dowling, 2009).

In this study I use the term 'recovery' to refer to an individual with a mental illness reclaiming their right to a safe, dignified, personally meaningful and gratifying life in their community while managing a challenging lifelong health condition. Learning to cope with the illness and achieving a desired quality of life are essential to recovery. Recovery emphasises self-determination and participation in typical life pursuits such as education, employment, sexuality, friendships, spirituality and voluntary membership in one's community (Davidson & Roe, 2007). This conceptualisation of recovery differs from common understandings of recovery as a 'cure' in which there is a complete absence of symptoms. Rather, recovery is viewed as a process of living with a severe illness and achieving independence, self-esteem and a meaningful life in the community. Fundamental to recovery are the skills and attitudes inherent in resilience: optimism, self-care, self-

determination, self-acceptance and resourcefulness. See section 2.5 for further discussion of the concept of recovery.

### 2.2 Resilience

In this section I present a historical overview of the development of resilience as a health, psychological and social construct. I discuss conceptual differences and common understandings in the fields of health and social care. I review the research evidence on which these understandings are based. I explore contemporary views about resilience, including research emphasising the significance of resilience in defining health and social outcomes. I also discuss how resilience is manifested and its role in maintaining optimum health and social functioning.

# 2.2.1 The Psychological and Social Concept of Resilience

The concept of resilience accommodates a wide variety of positions and interpretations. However, after an extended period of research and debate, broad agreements about what constitutes resilience and the conditions that foster its development are now evident. The emergence of the concept itself extends from the 1800s and continues to the present time (Jackson, Firtko et al. 2007). The term is derived from Latin origins meaning: 'to jump or bounce back' (Silliman 1984, cited in Seccombe 2002, p.385). The *Oxford English Dictionary* defines resilience as 'elasticity; the power of resuming the original shape or position after compression, bending' and as 'rebounding or springing back'. The lexical analysis of the term also includes adjectives such as 'cheerful, buoyant, and exuberant' (Agaibi & Wilson, 2005).

There is a clear consensus in the literature in a range of fields about the importance of resilience to healthy human functioning. However, definitions, characteristics and methods of measuring resilience vary. This can be attributed to the development of the construct

across diverse health, sociological and psychological fields (Gillespie, Chaboyer et al. 2007, Masten 2001, Ahern, Ark et al. 2008). The range of interpretations of the concept continues to challenge some of the broad understandings that have been established. However, despite differing health, psychological and social conceptualisations there is now a general consensus that all people have some level of resilience, with approximately one third of any population demonstrating 'high resilience levels' (Luthar 1991, Masten & Coatsworth 1998, Hauser 1999, Tusaie & Dyer 2004, Tusaie, Puskar et al. 2007).

# 2.2.2 The Evolution of the Concept of Resilience

Interest in the notion of resilience arose when researchers noted that there was significant individual variation in people's responses to similar trauma and/or risk experiences (Rutter, 2007). The construct become prominent in health and psychological research when Werner and Smith (1982) and Garmezy (1983) began publishing widely on the topic (Rouse, 1998). During this early period, resilience was conceptualised in different ways including as a trajectory, continuum, system, trait, process, cycle, and as a qualitative category (Rutter 1985, Jacelon 1997) (Tusaie & Dyer 2004, Bonanno 2004, Bonanno 2005, Jackson, Firtko et al. 2007).

Collective understandings about the psychological characteristics and influences on the development of resilience have predominantly come from longitudinal studies. These have primarily been conducted with children who have psychologically thrived despite difficult emotional, physical and social circumstances (Van Breda, 2001). Findings from these early studies have challenged existing negative assumptions and deficit-focused models about the development of children growing up under the threat of disadvantage and/or adversity (Masten, 2001). Views about resilience that emerged from these studies became the foundation for the development of more salient descriptions of resilience. These

descriptions have now become increasingly tailored to the domains of health, psychology and education.

The longitudinal research pivotal to developing awareness and understandings of resilience utilised a range of research designs. It primarily sought to identify predictors of the possible outcomes related to the experience of adversity (Werner & Smith 1982, Masten 2001). The research established the importance of resilience and continues to inform current thinking about the topic. For example, a longitudinal study conducted in Sweden by Cederblad, et al. (1994) provides one of the earliest examples of this research. This study commenced in 1947 and included children who were exposed to three or more factors associated with the later development of mental illness (Dahlin et al. 1990). A follow-up in 1988, when participants were in middle age, indicated that 'almost half the sample succeeded in creating a reasonably successful and at least moderately healthy life despite the severe handicaps in their childhoods ... It can be argued that at least half the sample has manifested considerable resilience' (Dahlin et al., 1990, p.231).

Similarly a seminal 40-year longitudinal study conducted by Werner (1982) identified children who, contrary to expectations, were coping successfully despite exposure to multiple social and environmental risks. This study commenced in 1955 with 200 children who were monitored from birth to age 32 years utilising a multifaceted assessment that determined the adjustment to risk (Werner, Honzik & Smith 1968). Findings from this research have challenged the traditional concept of resilience that suggested resilience was an individual psychological attribute. The researchers identified a range of life circumstances that they related to the development of resilience. These 'psychological protective factors' included individual personality traits, family environments, and evidence of supportive interpersonal relationships. The concept of protective factors that

can act as a buffer to negative psychological outcomes from risk, trauma and adversity is now established as a significant concept in the resilience field (Van Breda, 2001). These longitudinal studies were highly significant in that they focused on the development of psychological coping and thriving in 'at-risk' environments. They established links between resilience and trauma and positioned resilience in the context of psychological development defined through life experience(s). Later studies have confirmed and expanded the findings from the above research. For example, the findings from Werner's research were replicated in a study of the effects of trauma in childhood conducted by Bradley, Whiteside et al. (1994). This study included social conditions as a variable in defining the development of resilience. The researchers investigated the effects of environmental risk indicators such as poverty and low birth weight on the psychological development of children. They identified significant variability in children's responses to social and psychological stressors. One of the crucial conclusions to emerge from this study was that impoverished and stressful environments are not all the same and that they have inconsistent effects on children's social and emotional outcomes.

A large body of research also sought to identify the personal skills, behaviours and attributes that characterise resilience in childhood. These behaviours have been identified as responsiveness, determination, impulse control and the ability to elicit and receive positive attention from others (Rouse, 1998). Masten (2007) conducted a significant longitudinal study in this area titled 'Project Competence'. This research identified a range of personal characteristics and behaviours that characterise resilience and investigated their stability from childhood to adulthood. The study monitored 205 children and their families from the 1970s to the present and included the continuing participation of over 90 per cent of the initial population (Clinton, 2008). A finding to emerge from the research was that young adults who demonstrated resilience in their twenties also demonstrated similar

characteristics in childhood. These attributes included well-developed attending skills, agreeable personality, achievement motivation, conscientiousness, lower stress reactivity, positive self-concept, and academic, social and conduct competence.

Research such as Project Competence that identified the psychological attributes that characterise resilience led to an understanding that psychologically resilient individuals have an array of cognitive and behavioural competencies. These attributes are thus utilised to adapt to the demands of stressful or adverse situations. This emphasis is reflected in the description of resilience proposed by Johnston-Wilder and Lee (2010): 'combination of personal characteristics and skills that allow them to function beyond what may be expected in the light of that person's vulnerability or exposure to adversity' (Johnston-Wilder & Lee 2010, p.38).

Recent research in the field has further expanded understandings of the concept of resilience by highlighting the complex dynamics inherent in its development. Rouse (1998) proposes that in order to develop resilience an individual must draw upon all their biological, psychological and environmental resources. Similarly Waller (2001) asserts that resilience is not a static phenomenon but a psychological and social phenomenon individually defined by particular traumatic or adverse events. Connor and Davidson similarly describes the complex interplay of circumstances and characteristics that define resilience: 'resilience is a multidimensional characteristic that varies with context, time, age, gender, and cultural origin, as well as within an individual subjected to different life circumstances' (2003, p.76).

Cacioppo, Reis et al. also explored the social and interpersonal domains of resilience. The writers position resilience within a 'social capacity' framework. They contend that the

ability to endure and recover from life stressors includes the capacity to foster, engage in and sustain positive relationships: '[resilience is] the transformation of adversity into personal, relational, and collective growth through strengthening existing social engagements, and developing new relationships, with creative collective actions' (2011, p.44).

As research in the field progressed it established that trauma and/or adversity in childhood do not always affect psychological development to the extent that previous studies had suggested (Block & Kremen, 1996). Consequently more complex conceptualisations of resilience have been developed. In particular, deficit-focused models of trauma and/or adversity and its effects were further challenged by additional research indicating that a vulnerable person's life course was not necessarily pre-determined by childhood circumstances (Rouse, 1998). Consequently, an understanding that resilience is a multi-dimensional concept and that a diverse interplay of factors are involved in its development and manifestation emerged. For example, in a review of the research in the field, Fonagy (Fonagy, Steele et al. 1994) describes resilience as a complex environmental and psychological phenomenon. The author suggests that resilience development is contingent on the following interplay of factors:

- within-child factors, that is, high levels of cognitive ability and social competence,
   being female (up to the age of puberty), an even temperament, positive self-perceptions;
- domestic environmental factors, that is, socioeconomic status of parents/carers, education levels within the family unit, parental competence in childcare, parental responsibility;

 outside home factors, that is, neighbourhood influences, schooling characteristics (especially teacher expectations, peer influences, and the level of support available).

The concept that successful adaptation and the development of psychological competence in response to adversity are the foundations of resilience is now well established in resilience theory (Masten, 2001). Discussing the concept of adaptability, Werner (1990) maintains there is nothing extraordinary about resilient children who are able to flourish when faced with trauma and/or adversity. The author refers to the ordinariness of resilience as a function of basic human psychological adaptation systems. Similarly Luthar, Cicchetti et al. describe resilience as: 'a dynamic process encompassing positive adaptation within the context of significant adversity' (2000, p.1). The emphasis on adaptability suggests that individuals cannot be considered resilient if they have never experienced a significant threat or if they do not demonstrate evidence of positive adaption in response to experience(s) of trauma and/or adversity.

In exploring the notion of psychological adaptation/competence and skill development, a number of researchers suggest that resilience and coping are associated constructs (Luthar, Cicchetti et al. 2000, Masten 2001, Schilling 2008, Cohen, Ferguson et al. 2011). In this conceptualisation a distinction is made between coping as a set of cognitive and behavioural strategies utilised by individuals to manage the demands of stressful situations, and resilience as the adaptive outcomes arising from trauma and/or adversity (Folkman & Moskowitz 2004, Campbell-Sills, Cohan et al. 2006). Dutton and Greene (2010) have developed a resilience framework that illustrates this concept. This framework positions psychological adaptability in response to trauma as the foundation of resilience development. However, the authors expand the concept of resilience by identifying a range

of interrelated factors that contribute to its development. Therefore they suggest that resilience following exposure to adverse and/or traumatic events is a positive outcome of the interactions between an individual's psychologically protective factors (i.e. personality type, biological characteristics, social and cultural life factors) and psychological adaptation (i.e. self-enhancement, positive cognitive appraisals, coping styles and spirituality).

In summary, a consensus has emerged over the last thirty years that resilience is a complex phenomenon that develops from dynamic interactions within, and between, organisms and their environments. However, despite agreements about the concept, the field continues to accommodate a range of interpretations and positions (Jackson, Firtko et al. 2007). Terms continue to be used interchangeably to describe concepts such as hardiness, post-traumatic growth (PTG), buffering and psychological protective factors (Hatala, 2011). These inconsistencies are reflected in the measures used to assess resilience. Masten's definition of resilience attempts to broadly accommodate the range of interpretations in the field: 'resilience is best defined as a trait, a process, an outcome, a pattern of life course development, narrow or broad, multifaceted or unidimensional, short or long-term' (2007, p.924).

The study of the influences, patterns and pathways that can determine resilience is ongoing and new interpretations of the concept continue to emerge (Masten, 2001). In predicting future developments in the field, Vanderbilt-Adriance and Shaw (2008) note that research is only now beginning to inquire into the role of other factors that define resilience, such as biology and genetics (Haglund et al., 2007; Nigg et al., 2007). They also note that several studies have investigated genetic and environmental interactions in the development of resilience. They conclude that this research indicates that environmental risk is only

associated with negative outcomes in the context of genetic risk. However, as Bonanno (2004) points out, most research into the development of resilience, trauma and loss has tended to focus on people seeking treatment for mental illness. Consequently, little is known about the processes that help to determine the development of resilience in other (i.e. healthy) cohorts. Additionally, research into resilience has often been situated in the context of childhood development. Therefore, resilience in later life remains an underexplored area (Caspi, McClay et al. 2002, Jaffe & Hall 2005).

### 2.2.3 The Concept of Resilience: Personality and Biology

This section provides a summary of the most significant perspectives, terms and measures that have emerged in the research and literature on resilience. These perspectives, terms and measures are integral to the conceptual frame that I will apply to examine the phenomenon of resilience, CTA and psychosis in this research.

A fundamental difference in the resilience field that creates ongoing debate is whether resilience is a psychological process, a personality trait or a combination of both. In exploring the relationship between resilience and personality traits, Werner (1992) and Garmezy (1984) describe how personality may define an individual's resilience, particularly in children (Rak & Patterson, 1996). The authors define these characteristics as psychological capacities. These capabilities can consist of proficiency in problem solving that assists in negotiating emotional hazards, positive attention-seeking skills, an optimistic disposition, the ability to maintain a positive vision of a meaningful life, and the skills to be autonomous, alert, adventurous and have a proactive perspective. Furthermore, additional personality characteristics associated with resilience include internal locus of control, strong self-esteem, altruism, as well as a mature or developed ego defence (Agaibi & Wilson, 2005). Advocates of the concept of resilience as a personality trait view resilience as a measurable, stable developmental process that forms during an individual's

lifespan. They assert that a combination of physical and psychological characteristics provide the individual with the internal skills to be resilient (Hatala, 2011).

A number of personality factors have been identified as protective factors that can emerge in the face of both acute and chronic adverse situations. Luthar, Cicchetti and Becker (2000) note that, within groups of people exposed to significant psychological adversity, those with well-established psychological protective characteristics manage adversity better that those without. Protective traits have also been linked with extroverted personality characteristics such as hardiness (Kobasa, 1979). Some researchers also apply the terminology 'psychological hardiness' to describe individuals who are confident and have the capacity to appraise difficult or threatening situations as less distressing. They propose that these individuals are better able to use active coping skills and engage social support. This consequently enables them to achieve better outcomes following exposure to stress (Agaibi & Wilson, 2005). Other researchers such as Clinton (2008) have examined resilience from an adaptive behavioural perspective, in particular the interactive relationships between a child's biology and their environmental conditions. Clinton concludes that neither biological characteristics nor environmental influences alone account for resilience.

The notion that biology can define resilience has been challenged by research that links external social and cultural factors to the development of traits inherent in a resilient personality. For example, a number of studies have identified how gender can influence an individual's ability to manage psychological stress and trauma (Dutton & Greene, 2010). In a matched case-control longitudinal study of young adults, Roy (2011) identified a greater tendency for resilience in women who had experienced trauma and/or adversity as children compared with men. Roy observed that one in five of their research sample

demonstrated resilience overall, but that gender differences were evident with a higher proportion of young women (27%) demonstrating resilience compared to young males (18%). Conversely, research also suggests that resilience is not entirely gender specific, nor is it a phenomenon that necessarily increases or decreases with age (Agaibi & Wilson, 2005).

Writers and researchers who question the view of resilience as a personality trait argue that adaptability to adverse circumstances as noted above is fundamental to resilience development. Dutton and Greene (2010) contend that resilience is not comprised solely of innate biological or personality characteristics. They maintain that resilience development is an evolving process that includes the dynamic interactions between positive psychological attributes, child-rearing experiences and socioeconomic conditions. Supporting this view, Mancini and Bonanno (2006) assert that it is uninformative to describe an individual as having a resilient personality, as resilience can only be defined 'ex post facto' (i.e. resilience can only be determined following a resilience-defining event). Papousek (2011) also asserts that resilience is neither a personality nor an inborn trait as was once thought. She also suggests that the interactions between personality attributes and environmental factors begin early in a child's development and become embedded in the regulatory processes involved in the caregiver—infant system.

These views align with the concept of resilience as the manifestation of a complex interaction of factors with origins determined by both genetic and environmental contexts. Integral to this concept is the notion that resilience is only exhibited by indicating some emotional and psychological adjustment. Bensimon (2012) suggests that this concept emphasises that the process of resilience development culminates in permanent psychological reconfiguration enabling individuals to rebound from trauma and adapt to

change. As Bensimon notes, 'depending on how one considers resilience, it may be promoted by a broad cluster of personal characteristics that facilitate the ability to manage and even prosper despite trauma, much like growth' (2012, p.783).

The debate about whether resilience is either a biological or personality trait or a learned psychosomatic adaption mechanism has important implications for understanding how resilience may be utilised as a psychological tool to enhance functioning. If resilience is conceptualised solely as a personality or biological trait, it is assumed to be a set and immutable attribute. However, if it is viewed as a dynamic psychological set of 'skills' that enable individuals to adapt to adverse circumstances, the implication is that these can be enhanced through either external or internal influences.

# 2.2.4 Psychological Protective Factors

Psychological protective factors are viewed as the building blocks of resilience and have been described as the internal and external resources that individuals draw upon to assist, modify or buffer the influence of psychological risk factors from trauma and/or adversity (Smokowski, Mann, Reynolds & Fraser, 2004).

Relevant to this PhD study is research that has focused on investigating the links between protective factors and resilience in individuals who have experienced trauma and/or adversity, particularly CTA (Kinard 1998; McGloin & Widom 2001). A number of studies have established the role that protective factors have in resilience in the context of trauma. For instance, research by Hyman and Williams (2001) highlighted the importance of protective factors in developing and enhancing resilience in the context of trauma. The researchers investigated psychological protective factors and their relationship to resilience utilising a sample of sexually abused young females. The research cohort was interviewed both as children and later in adulthood. The research identified that the most significant

predictors of resilience were associated with external factors such as a stable family, less severe traumatic experiences as a child, no history of juvenile arrests, graduation from high school, and no history of sexual victimisation in adulthood. This research has been fundamental to enhancing understanding about ways to promote resilience, health and wellbeing for people with the experience(s) of CTA (Afifi & MacMillan, 2011). However, questions remain as to whether psychological protective factors are independent, positive factors in their own right or whether they only have an effect when there are risk factors that need to be alleviated.

Evidence about protective factors and their role in enabling people to cope with adversity contradicts the view that resilience is an acquired skill. It suggests that some level of personality trait is a central determinant of the capacity to cope with CTA in adulthood. Nevertheless, congruence has emerged in the field in regards to the range and interplay of protective factors that are associated with an individual's capacity to manage adversity and trauma. Burt (2002) suggests that these factors can be divided into the following three categories:

- personal or individual characteristics or attributes of a person;
- characteristics (i.e. resources) within a family structure, particularly in child rearing;
- characteristics of formal and informal social support networks into which one might be connected (Pollard, Hawkins & Arthur 1999; Smokowksi, Reynolds & Bezruczko 1999).

These psychological 'categories' align with the factors inherent in the development of resilience identified by Fonagy et al. (1994) described earlier in this review. However,

researchers such as Afifi and MacMillan (2011) assert that there are limitations to the empirical base regarding protective factors. They suggest that a more detailed analysis of the associations between protective factors and resilience needs to be conducted to strengthen the evidence base. Despite these reservations, the evidence base to date indicates that individuals are able to draw on a variety of psychological protective factors to cope with the detriments associated with adversity and/or high-risk environments. These are clearly dependant on the many varied interactions between an individual's internal 'psychological constitution' and the external environmental factors that can circumscribe their lives and experiences.

# 2.2.5 Trauma Prevalence, Post-Traumatic Stress Disorder (PTSD) and Post-Traumatic Growth (PTG)

Traumatic and adverse events appear to be experienced by approximately 60 to 90 per cent of the general population. These have been linked to a range of mental health consequences (Hartman, Turner et al. 2009). PTSD is a disorder that affects 5 to 10 per cent of people exposed to an intensely threatening, traumatic event (Fetzner et al. 2011). The Diagnostic and Statistical Manual of the American Psychiatric Association (2013) defines PTSD according to several symptoms categorised as: re-experiencing (i.e. relentless nightmares, unbidden waking images, flashbacks); hyperarousal (i.e. enhanced startle, anxiety, sleeplessness); and phobias (e.g. fear of driving following an automobile accident). Furthermore, PTSD often demonstrates a chronic course with as many as 40 per cent of individuals exhibiting significant symptoms a decade or more following onset (Edwards & Loeb, 2011). Health problems are also associated with PTSD such as obesity, and increased rates of smoking, asthma, cancer, stroke (Dobie, Kivlahan et al. 2004) and suicide (Kessler, Sonnega et al. 1995, Edwards & Loeb 2011).

Not all individuals exposed to traumatic events will develop psychological symptoms related to the experience (Little, Akin-Little et al. 2011). Some demonstrate resilience and the ability to thrive despite their exposure to severe emotional stressors (Tarrier & Gregg, 2004). Research in the trauma field has generated the concept of PTG. This is defined as a psychological outcome resulting from the successful use of specific psychological coping skills developed following exposure to trauma and/or adversity (Joseph & Butler, 2010). PTG covers a wide range of outcomes from individuals faced with diverse trauma and adversity experiences (Steele & Kuban, 2011). PTG is not simply a return to baseline psychological functioning following these experiences. Instead, it is an experience that for some individuals is profound. Tedeschi and Calhoun define PTG as a 'positive psychological change experienced as a result of the struggle with highly challenging life circumstances' (2004, p.1). These changes can include an enhanced ability to relate to others, a gratitude towards life, spiritual changes and an appreciation of one's strengths (Tedeschi & Calhoun 2004). The evidence about the effects of PTG is predominantly based on individuals' subjective or 'perceived' accounts of positive change following trauma (Calhoun & Tedeschi, 1996). However, in the field of resilience there has not been an extensive theoretical and research focus that has explored the development of resilience following a specific traumatic event (Steele & Kuban, 2011). Moreover, concepts relating to PTG and resilience are sometimes applied interchangeably in the literature (Gerrish, Dyck et al. 2009). There are also claims that PTG is a form of psychological growth that is 'superior' to resilience (Tedeschi, Calhoun et al. 2007, Levine, Laufer et al. 2009). However, a question that remains unanswered across both the PTSD and mental health recovery fields is why some people experience PTG and develop resilience in response to trauma and/or adversity when for others it can have serious long-term psychological and physical consequences. Unravelling the answers to this complex question has implications for understanding illness recovery, and for how illness is treated.

### 2.2.6 Resilience and Social Contexts

As I have stated, resilience theory is now firmly grounded on the premise that an individual can prosper in the face of hardship. The empirical evidence on which this premise is founded demonstrates that the presence of support structures within the family and community, combined with individual protective factors, is pivotal in the development of resilience. The lack of consensus that continues to define the field arises from the different conceptual emphases that researchers have placed upon the resilience concept. As one of my intentions in this research is to examine resilience in the context of psychosis and CTA, my discussion of resilience will extend beyond the longstanding debate about its development to include consideration of the effects of social, cultural and economic factors on resilience development. This includes exploring complex interweaving factors such as poverty and social capacity on health and social outcomes including the influence of resilience in enhancing the functioning of people living in complex circumstances.

However, in a discussion of the multiple effects of social disadvantage on resilience, both Westphal (2007) and Rouse (1998) caution against overly simplistic interpretations of the relationships between poverty and psychological phenomena such as resilience. In challenging the deficit assumption that all impoverished and stressful environments are social and emotional vacuums, both authors emphasise that a range of complex genetic, health, social and familial influences can determine resilience. In supporting the conclusions arising from the research previously cited by Werner, Honzik et al. (1968, see Seccombe, 2002) and Cederblad, Dahlin, et al. (1994), the researchers also draw attention to the combination of factors in impoverished environments (i.e. specific child-rearing practices, and familial and community responses) and personality characteristics that assist the development of resilience. They suggest that these external factors may mitigate the potential negative effects of adversity.

### 2.2.7 Resilience Measures in Psychological, Health and Social Research

A review of the resilience literature indicates that a variety of approaches are used to measure resilience across the field. As I have discussed, there are divergent perspectives about the construct that continue to characterise the field. Consequently, these are reflected in a lack of consistency and agreement about the measurement of resilience (Campbell-Sills & Stein, 2007). Until recently, resilience measures used in research have commonly comprised self-reports, such as the Conner-Davidson Resilience Scale (CD-RISC-25 items) (Connor & Davidson, 2003) and the Resilience Scale for Adults (RSA-37 items) (Wagnild & Young, 1993). Furthermore, only two studies in the mental health field have utilised standardised measures to investigate resilience in the context of psychosis (see Georgiades, Farquharson et al. 2014). Longitudinal studies that have investigated resilience across diverse social groups illustrate that different ways of measuring resilience impact on the strength of empirical evidence across the field (Forrest & Kearns, 2001). This can be attributed to the difficulty of comparing the prevalence and veracity of resilience across different studies, even when the study populations has experienced similar rates and types of psychological 'events'. Ahern et al. (2006) observes that the use of different resilience measures has increased conceptual ambiguity in the field. Similarly, Rutter (2000) and Vanderbilt-Adriance and Shaw (2008) assert that, although numerous studies define resilience, only a limited number have used reliable measures to compare resilient and non-resilient groups.

Moreover, aside from qualitative measures, there are few reliable and valid quantitative measures designed to assess resilience in unique social and health populations. This has hindered the development of understanding about how resilience is developed and manifested in these populations. I will address this issue in greater detail in Chapters 4, 6 and 8, including the use of the resilience measure called the Resilience Scale, with a

regionally representative psychosis population. As Rutter and Sroufe (2000) observes, there are difficulties measuring a complex construct such as resilience that is manifested in diverse ways. Rutter also notes that overcoming trauma and/or adversity can also be dependent on experiences following risk exposure. Therefore it may be important to consider a lifespan perspective when assessing an individual's resilience: 'resilience cannot be reduced to what is involved in the chemistry of the moment of exposure [and] resilience cannot be equated with individual psychological traits, however conceptualized' (Rutter, 2007, p.205).

## 2.2.8 Resilience in Summary

Over the last three decades a broad consensus about the construct of resilience has emerged. While agreement about the construct is evident, some ambiguity and contradictions regarding definitions, and the manifestation and development of resilience are evident (Luthar, Cicchetti & Becker, 2000). Fundamentally, resilience has been defined as the ability to adapt and cope successfully despite threatening or challenging situations. According to Agaibi and Wilson (2005), resilience is a positive outcome of trauma and/or adversity, despite significant psychological demands, costs, stressors or personal risk to the individual. Given this, there is now extensive research that has provided robust evidence demonstrating that some individuals are able to cope, adapt and thrive despite adverse circumstances.

Researchers and theorists in the field have attributed this finding to a range of environmental and personality resources that individuals draw upon to mitigate the negative impact of adverse psychological circumstances. A comprehensive research base has described the nature of these psychological and environmental resources and their interaction in the development of resilience. However, diverse views, emphases and interpretations about these factors and processes continue to characterise the field. Earlier

views of resilience, as either an environmental phenomenon or as a personality trait, are now regarded as overly simplistic.

Incorporated into the current knowledge base is the conceptualisation of resilience as a dynamic, multi-dimensional phenomenon. This conceptualisation is based on the understanding that complex, interweaving processes contribute to the development of resilience. This construct is well grounded in the literature in the field. Central to current understandings of resilience is the notion of psychological adaptability in response to trauma and/or adversity. In this thesis I subscribe to the view of resilience as an individual's emotional flexibility and/or psychological capacity to recover from trauma and cope with major difficulties and disadvantages in life. This concept incorporates the primary elements that describe resilience proposed by researchers such as Bonanno (2004), Luthar, Cicchetti and Becker (2000), and Dent and Cameron (2003) who have significantly influenced the study of resilience. This understanding of resilience is also congruent with the principles that underlie the practice of illness recovery explored throughout this research.

# 2.3 Psychosis

In this section I will present an overview of the aetiology of psychosis, its prevalence, manifestation, and the effect of psychosis on health and psychosocial functioning. I examine the relationship between trauma and/or adversity and psychosis. I also explore the effects of stigma, poverty and disadvantage on the ability of people with a psychotic illness to establish social roles and lead meaningful lives in their communities.

### 2.3.1 The Symptoms and Prevalence of Psychosis

Psychosis is defined as the presence of hallucinations and delusions and is present in a number of psychiatric disorders including schizophrenia, delusional disorders,

schizoaffective disorders and drug-induced psychosis. Schizophrenia is a major mental illness characterised by psychosis, apathy, social withdrawal and cognitive impairment. These symptoms can result in impaired functioning in work and school, and can affect parenting, self-care, independent living, interpersonal relationships and leisure time (Mueser, 2004). Psychotic symptoms can also sometimes develop in bipolar disorder and major depressive disorder. Acute transient psychotic disorders can also occur. Subclinical psychotic symptoms can be found in the general population without reaching a threshold for diagnosis of a psychotic disorder. Young people with subclinical psychotic symptoms are referred to as 'at risk' of developing psychosis. However, most do not make the transition to a clinical psychotic disorder.

The symptomology of psychosis can include positive symptoms including unusual thought content, suspiciousness, hallucinatory behaviour and conceptual disorganisation. Negative symptoms, such as depressed mood, low energy, lack of motivation (apathy), social withdrawal and affective flattening (Miller, McGlashan et al. 2003, Birchwood, 2003) are also common. Van Os et al. (2010) have identified the symptoms of psychotic syndrome as: psychosis (hallucinations and delusions), motivational impairment (avolition<sup>2</sup> or amotivation<sup>3</sup>), affective dysregulation<sup>4</sup> (depression, mania) and alterations in information processing (cognitive impairment). Many people with psychosis can also exhibit deficits in attention, concentration, short-term memory, motivation, planning, decision making and sense of pleasure (Sharma, 1999). The prevalence of psychotic illness is comparatively low in the adult population (approximately 1.0%) compared to other mental illnesses such as major depression (Jonas, Brody et al. 2003, Kessler, Berglund et al. 2003, Craddock,

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<sup>2</sup> Avolition: a psychological state characterised by general lack of drive, or motivation to pursue meaningful goals.

<sup>&</sup>lt;sup>3</sup> Amotivation: a state of lacking any motivation to engage in an activity characterised by a lack of perceived competence and/or a failure to value the activity or its outcomes.

<sup>&</sup>lt;sup>4</sup> Dysregulation: impairment of a physiological regulatory mechanism (such as that governing metabolism, immune response or organ function).

O'Donovan et al. 2005). Nonetheless, extensive evidence confirms that psychosis remains one of the leading causes of disability, morbidity and mortality worldwide (Murray & Lopez 1997, Harris & Barraclough 1998, Gil, Gama et al. 2009).

The dominant symptoms of psychosis such as delusions and hallucinations can significantly hinder a person's ability to function. Schizophrenia is the most common form of psychotic illness and is linked to genetic determinants and neurodevelopmental<sup>5</sup> origins. In Australia, psychotic illnesses are generally treated with antipsychotic drugs and, although 70 per cent of users indicate some level of improvement in psychotic symptomatology when using medication, many still experience distressing and recurrent symptoms throughout their lives (Curson, Patel et al. 1988, McCann, 2001). Psychotic illnesses such as schizophrenia have been subjected to detailed genetic epidemiological investigation (Craddock, O'Donovan et al. 2005). A number of family, twin and adoption studies have established that the risk of schizophrenia increases among the relatives of affected individuals. This has largely been attributed to genetics rather than a shared environment (McGuffin, Owen et al. 1994, Craddock, O'Donovan et al. 2005). These studies have informed understandings about the prevalence, symptomology and treatment of the illness. However, there is also a developing body of research that suggests factors such as social and economic circumstances at birth or during childhood may also be causally related to the development of a psychotic illness. These include early life adversity, growing up in an urban environment, social, race and gender position, and cannabis use (Van Os et al. 2010).

Research indicates that individuals who develop psychotic illnesses such as schizophrenia are more likely than their peers to have experienced developmental delays and cognitive

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<sup>&</sup>lt;sup>5</sup> Neurodevelopmental: refers to the belief that the origins of adult mental illness are located in disturbances of development of the nervous system.

impairments as children. Moreover, children who develop schizophrenia as adults have been described as tending to be more solitary and socially anxious (Jones, Murray et al. 1994, Cannon, Caspi et al. 2002, Broome, Woolley et al. 2005). Other studies have reported that individuals who develop schizophrenia also demonstrate a reduced capacity to learn new cognitive skills as they enter adolescence (Jones, Murray et al. 1994, Fuller, Nopoulos et al. 2002, Broome, Woolley et al. 2005). Current research in the field of psychosis is strongly focused on deepening understanding of the neurobiological conditions that may be determinants of the illness. This includes attempts to identify specific genes linked to the condition. There is also a current focus on exploring psychosocial factors as one of the possible determinants of psychosis (Morrison, Frame et al. 2003). This includes identifying possible links between poor social environments and psychosis. There is also increased interest in investigating the links between early environmental experiences and the development of psychotic illnesses in adulthood (Cantor-Graae, 2007). These investigations position psychosis within a health and social framework. They aim to deepen understandings of the illness by highlighting the connections between the psychological, social and biological processes that may contribute to the aetiology and course of the illness.

## 2.3.2 CTA and Psychosis

As discussed, a significant evidence base confirms the existence of causal links between CTA and a range of mental illnesses in adulthood (Spataro, Mullen et al. 2004, Read et al. 2005, Cutajar et al., 2010), including psychosis (Dvir, Denietolis et al. 2013, Larkin & Read, 2013). For example, a review conducted by Read et al. (2005) identified the relationship between CTA, psychosis and schizophrenia. This review examined studies involving psychiatric inpatients and outpatients of whom at least 50 per cent were diagnosed with a psychiatric condition. The researchers produced weighted averages for females and males with CTA and found that in 51 studies 48 per cent of females and 28

per cent of males reported child sexual abuse. This included incest (29% females, 7% males) and child physical abuse (48% females, 50% males) (Morgan & Fisher, 2007).

In a further literature review of 59 studies involving psychiatric inpatients and outpatients, Read, Fink et al. (2008) identified that, on average, the incidences of CTA such as child sexual abuse averaged 47 per cent for females and 29 per cent for males, while child physical abuse was 47 per cent for females and 49 per cent for males (Amr, El-Wasify et al. 2010). Similarly, Janssen, Krabbendam et al. (2004) conducted an analysis of 4045 subjects aged 18 to 64 drawn from the Netherlands Mental Health Survey and Incidence Study. This study established that individuals who had experienced emotional, physical or sexual abuse, or neglect before the age of 16 were more likely to report experiencing psychotic symptoms during the three-year follow-up period of the study (Morgan & Fisher, 2007). Bendall, Jackson et al. (2008) similarly reported a high prevalence of CTA (between 28% and 73%) in people with psychosis. Furthermore, CTA, such as abuse by an adult and bullying by peers, has been associated with the development of psychotic symptoms in children and an increased risk of psychotic illness in adulthood (Arseneault, Bowes & Shakoor, 2010). A study by Spauwen et al. (2006) involving 2,524 adolescent trauma survivors identified CTA as having a significant role in the development of positive symptoms of psychosis. This substantial study provided robust evidence about the relationship between CTA and psychosis, as comprehensive follow-up for symptoms of psychosis was conducted over an average period of 42 months (Steel, Marzillier et al. 2009). These studies have contributed to a strong evidence base demonstrating that CTA causes prolonged suffering that can lead to highly distressing psychological and physical consequences. For some people the experience of CTA increases the risk of developing major psychiatric disorders such as psychosis (Morgan & Fisher, 2007).

Morgan and Fisher (2007) assert that evidence from the most recent studies in the field confirms the existence of links between CTA and psychosis. However, they point out that results have not been consistent across studies and that the research has been characterised by complex conceptual and methodological issues. There are also some questions about the reliability of some of the measures of CTA. For example, many of the studies rely on retrospective self-reports of CTA that may have been contaminated by memory error or bias. Additionally, different methods of assessing trauma and/or adversity have been used in CTA research. These have been found to lead to different rates of disclosure of the type of abuse experienced by research participants (Bendall, Jackson et al. 2008). Confidential self-report measures can also yield twice the number of CTA histories than general questions asked in a psychiatric intake interview for female inpatients (Dill, Chu et al. 1991).

# 2.3.3 Psychosis and Social Disadvantage

The relationship between poverty, social disadvantage and poor health outcomes has been firmly established in an extensive body of research (Burns & Esterhuizen, 2008). For example, a large United Kingdom survey of 8,191 adults conducted by Weich et al. (1998) established a positive relationship between income inequality and mental illness. Research has also confirmed that social disadvantage and poverty are more strongly related to schizophrenia and other psychotic disorders than other mental illnesses (Read, Fink et al. 2008). This relationship has been consistently identified across diverse cultural, social and demographic contexts (Cederblad, Dahlin et al. 1994). For example in a Swedish study of migrant households, Hjern et al. (2004) examined factors related to social adversity, such as parental unemployment, single-parent household, urban residence, adults receiving social welfare benefits, housing and parental social status of people with psychosis. The study compiled rates of psychoses for adult and youth first-generation migrant cohorts. When rates for these groups were compared to native Swedes and adjusted for household

indicators of social adversity, a sizable proportion of the elevated rates of schizophrenia in the adult group, and to a lesser extent in the youth group, were attributed to social and economic disadvantage (Cantor-Graae, 2007).

Psychotic illnesses such as schizophrenia are recognised as particularly disabling disorders, which can have poor outcomes for individuals and their families (Erritty & Wydell, 2013). Individuals with psychosis can often experience a reduction in their quality of life and impaired social functioning (Moriarty, Jolley et al. 2012). The illness is associated with multiple social disabilities in work, study, independent living, interpersonal relations and self-care, and serious disability in functioning is one of the core features of the DSM-V diagnosis of schizophrenia (Velthorst, Nieman et al. 2010). Unemployment in psychosis populations is also common, with a corresponding increase in social stigma (Ramsay, Stewart et al. 2012). The ongoing challenge of managing a psychotic illness, particularly schizophrenia, can preclude people from managing the demands of employment and general economic participation. Consequent poverty can exclude individuals from access to the social opportunities and economic participation enjoyed by others. Consequently psychosis is associated with increased risks of poverty.

Moreover, psychotic illnesses such as schizophrenia often become manifest at a time of critical importance in social development, educational attainment and employment seeking (Turner, Brown, et al. 2009). Low levels of employment ((Ramsay, Stewart et al. 2012), diminished social mobility (Weich & Lewis, 1998), low capacity for productivity (Fox, 1990), limited educational attainment and poor physical health (McDaid, Jenkins et al. 2011) can create social and economic isolation. Employment not only provides an income; it creates opportunities for social interaction and enhances independence and self-worth. While high unemployment is not necessarily endemic to psychosis populations, a recent

UK psychosis study reported that 40 per cent of all disability allowance was directed to people with mental illnesses such as schizophrenia (Marwaha & Johnson, 2004). The relationship between social disadvantage and poor health status is also clear. People who have a psychotic illness exhibit higher rates of obesity (Lorant, Deliege et al. 2003), poor physical health comorbidity (Taylor, McIntyre et al. 2012), and higher rates of substance abuse than the general population (Sim, Swapna et al. 2004). Homelessness and chronic levels of ill health exacerbate high levels of social disadvantage and poverty among this population (Addington & Addington, 2007).

The relationship between these interrelated factors can thus create disadvantage. This disadvantage can have multiple negative health and social outcomes. It limits access to social services and limits participation in broader economic and cultural opportunities accessed by healthy populations. Limited access to services, in turn, can further heighten vulnerability to poorer health, social and economic outcomes, and exacerbate marginalisation within the communities in which psychosis populations live. Moreover, rates of psychosis are higher in disadvantaged communities (March, Hatch et al., 2008), and illnesses such as schizophrenia are more prevalent in poor communities that also have higher levels of socioeconomic inequality (Boydell, Van Os et al. 2004). Residing in a community also exacerbate socioeconomic disadvantaged may disadvantage. Disadvantaged communities do not always have strong economic foundations, local organisational capacity or community assets that can provide a social and health infrastructure required to sustain complex needs. As a consequence they can be characterised by poor social cohesion and complex social and economic challenges (Wilkinson, Pickett et al. 2009).

### 2.3.4 Psychosis, Social Capital and Social Defeat

The theory of social capital illuminates the complex interrelationship between individuals, communities and social disadvantage. It highlights how poverty and disadvantage are a central part of the societal processes and dynamics of certain communities. These processes and dynamics can create an environment of significant psychosocial and health difficulty for some people, particularly those with a mental illness. The theory describes communities as sites for social connection, relationships, identity, and shared norms and values (Coleman 1988, Forrest & Kearns 2001, Bourdieu 2006). It suggests that empowerment and collective action emerge from a community's social capital, enabling it to collectively 'define, assess, analyse and act' (Labonte & Laverack 2001, p.114). However, when significant numbers of vulnerable people are located in geographically defined locations this can diminish the strength of the social capital in those communities. As I have discussed, people who are vulnerable because of poverty and mental illness may experience a range of barriers to participation in work, education and social networks. Their exclusion not only has a profound impact on their health and wellbeing; it has a reciprocal impact on the health of the community (Cattell 2001, Forrest & Kearns 2001).

Exclusion is central to the concept of social defeat. It provides an additional lens through which to understand the effects of disadvantage on individuals with a mental illness. Discussing the theory of social defeat, Selten and Cantor-Graae assert that 'chronic and long term experience of social defeat' (2005, p.110) is common among groups where there is a high prevalence of schizophrenia, including migrants, drug users and people with low IQ (Whitley, 2011). The theory describes the 'subordinate position' and 'outsider status' (Selten & Cantor-Graae, 2005) of individuals as a result of an 'actual social encounter in which one person physically or symbolically loses to another one' (Luhrmann, 2007). Writers in this field propose that there are several long-lasting effects of social defeat such as behavioural changes, and neuroendocrine and neurobiological effects (Buwalda, Kole et

al. 2005), which can adversely influence health, and psychological and social functioning (Ruis, Te Brake et al. 1999). In discussing the theory in relation to people with psychosis, Koolhaas et al. (1997) suggests that social defeat can exacerbate human psychopathologies, including depression and anxiety, which thereby creates further social and community isolation.

## 2.3.5 Psychosis and Stigma

Integral to exclusion and consequent 'social defeat' is stigma. As I have stated, research in the field of mental health has convincingly demonstrated that a psychotic illness can elevate disability levels and exacerbate social and health disadvantage. Allied to social disadvantage is stigmatisation and discrimination. The manifestation of stigma includes discrimination experienced across diverse social and economic environments, including in the workplace, family and social groups, as well as in the broader community (Lloyd, Sullivan et al. 2005). Discrimination and stigma are demonstrated in ways that negatively affect the self-concept of the individual (Angell & Test, 2002). This can occur through either the disruption of educational and vocational pursuits, or from the restriction of typical social and community activities (McGorry & Edwards 1997, Lloyd, Sullivan et al. 2005). Stigma is perceived as both public stigma (i.e. negative stereotypes in the community) and self-stigma (i.e. applying stereotypes to oneself and internalising them). The prevalence, perception and impact of stigma in the context of psychosis have been comprehensively examined in the Australian Commonwealth Department of Health and Ageing report People living with a psychotic illness report (2010). Another report, Parents with serious mental illness: Differences in internalised mental illness stigma and gender stigma between mothers and fathers (Lacey et al. 2014) describes how parents with psychosis often experience stigma that affects their parenting, including the perception of stigma externally (public stigma) and internally (self-stigma). Reports such as these highlight that up to 40 per cent of people diagnosed with psychosis experience discrimination and stigma at some time in their lives. Additionally, 20 per cent of people with a mental illness also choose not to participate in their local community due to actual experience of stigma or the potential that it may be experienced.

Stigma and discrimination can also be intensified by social skills deficits and/or the abnormal behavioural characteristics often associated with psychosis. These may produce uncomfortable or aversive responses from others (Ertugrul & Ulug, 2004). The potential for stigma is heightened by negative community perceptions and broad social attitudes towards people with mental illness. Torrey investigated social stigma associated with mental illness and concluded that schizophrenia is now regarded as the 'modern-day equivalent of leprosy' (2006). Confirming this finding is a study by Sanseeha et al. (2009) that explored community perceptions about mental illness. The researchers noted that in some communities schizophrenia was viewed as a chronic and incurable disorder and individuals with the illness experienced discrimination and stigmatisation. Participants with mental illness in this particular research perceived discrimination as a significant barrier to their recovery as it diminished their opportunities to develop a valued social role and a positive identity.

Stigma also extends to other domains of social and vocational life. Research indicates that people with a mental illness may attempt to conceal their illness from significant others such as employers, relatives or potential partners to avoid rejection or a sense of social failure. Lack of disclosure can extend to limiting social interactions to only those who are aware of, and accept, the illness. It can include a complete withdrawal from any social interaction at all (Link, Struening et al. 1997, Kleim, Vauth et al. 2008). In addition to these social and psychological consequences, stigma can also decrease the likelihood that people with a mental illness will seek mental health care (Corrigan 2004, Servais & Saunders 2007). Therefore, perceptions of stigma about mental illness can have an adverse effect on the lives of people with a mental illness (Corrigan & Watson 2002, Reinke,

Corrigan et al. 2004). Additionally, these perceptions and experiences are particularly profound during the important emotional and social development years of adolescence (Lloyd, Sullivan & Lee-Williams, 2005), when the early onset of psychosis is often manifested.

# 2.3.6 Psychosis in Summary

Psychotic disorders are complex illnesses that can have a profound long-term health, psychological and social impact on the individual. Research in the field indicates that complex, interrelated factors can determine the aetiology and course of the illness. There is also strong evidence pointing to the relationship between the experiences of trauma and/or adversity and the development of psychosis, including a correlation between trauma in childhood and the development of psychosis.

Psychosis can predispose a person to increased risks of social disadvantage and poverty through a lack of access to employment, low educational attainment, poor psychological health, risk of social stigma and/or the development of poor physical health. A range of psychosocial influences can also affect how the illness is manifest. Furthermore, well-documented negative community perceptions about mental illness create stigma and intensify social and community discrimination. Stigma in turn impacts on how people with psychosis are able to engage with their communities. The theories of social capital and social defeat encapsulate the complex interweaving of the effects of psychosis on individuals and their communities.

However, concerns regarding the validity of some of this research have been raised. For example, Steel, Marzullier et al. (2009) suggest there is a lack of methodological rigour in the design and reporting of data in some studies. The authors propose that research on the aetiology of psychosis has not focused sufficiently on investigating the highly complex

interactions between genetic and environmental factors. A number of researchers have also noted that social factors such as poverty, social disadvantage and consequent social exclusion can also be among several contributing causes of psychosis. These authors suggest that these factors have been neglected in favour of the advancement of knowledge regarding genetic and biological aetiologies (Larkin & Read, 2008). Therefore, although the links between trauma and/or adversity and psychosis are relatively well established, further exploration of the history of CTA in people with a psychotic illness is required in order to illuminate the complexities and interrelationships of these links and their implications for mental health praxis (Krabbendam, 2008).

As I have discussed, the experience(s) of trauma and/or adversity can have diverse influences on psychological and social functioning. There are also complex mediating factors that affect an individual's capacity to achieve positive life outcomes despite their experience(s) of trauma and/or adversity. Trauma and/or adversity in childhood may be only one of many factors correlated to the development and trajectory of psychosis. The central question that remains relatively unexplored in the research literature concerns the defining factors that influence the recovery of an individual with a psychotic illness from the experience(s) of CTA. Related to this question is how the experience(s) of CTA affects the capacity of an individual to manage the impact of their illness on health, and psychological and social functioning.

# 2.4 Childhood Trauma and/or Adversity (CTA)

The following section provides an overview of the field of trauma and/or adversity. I focus specifically on trauma and/or adversity in childhood and how it is psychologically and socially manifest in adulthood. I review current knowledge about the prevalence of trauma and/or adversity and highlight its effects on psychosocial development and healthy adult functioning. I identify common understandings about trauma and/or adversity, together

with the research evidence on which these are based. Finally, I examine the relationship between CTA and resilience.

The terminology related to childhood trauma and/or adversity (CTA) used in this literature review delineates the broad spectrum of either single or multiple traumatic and/or adverse experience(s). Therefore, I use CTA to refer to abuse (i.e. physical, emotional or sexual abuse), personal tragedy, illness (i.e. psychological and/or physical illness), and social isolation, poverty, neglect, and/or family breakup. I also use the singular term 'trauma' to describe the experience(s) of traumatic and/or adverse events. I make no attempt to define CTA according to any specific criteria, such as the severity of abuse or to categorise CTA types according to severity.

# 2.4.1 Conceptualisations of Trauma and Adversity

As with resilience, there are differences in the conceptualisations, descriptions and definitions of psychological trauma and/or adversity. Consequently, definitions of CTA can be inherently problematic (Bendall, Jackson et al. 2008). The terminology of trauma, adversity and early life stress are often used interchangeably across diverse social and health contexts. In discussing the different interpretations of trauma and adversity, Brown et al. (1999) provide a description that encapsulates the dimensions of trauma and/or adversity proposed by a number of authors in the field. This concept of trauma and/or adversity encompasses child abuse and neglect including verbal assaults on a child's sense of worth, bodily assaults that pose risk of injury, sexual contact, failure to meet basic psychological or emotional needs, and failure to meet basic physical needs (Bernstein & Fink 1998, Browne & Winkelman 2007). In a discussion about the use of different terminology, Petchel and Pizzagalli (2011) refer to Brown's et al. (2009) description of trauma and/or adversity as definitive. Petchel and Pizzagalli similarly define trauma and/or adversity as 'physical, sexual, emotional or verbal abuse, neglect, social deprivation,

disaster or household dysfunction (including witnessing of violence, criminal activity, parental separation, parental death or illness, poverty, substance abuse)' (Pechtel & Pizzagalli 2011, p.55).

As Pat-Horenczyk and Brom (2007) note, trauma is a complex phenomenon. It can be defined by the experience(s) of trauma as well as by how an individual psychologically copes with the trauma. Discussing this complexity, Shaw (2000) makes an important contribution to understanding the concept by distinguishing between the following primary categories of trauma and its origins:

- event trauma: the sudden unexpected occurrence of a stressor, which is limited in time and space, and
- 2. process trauma: continuing and unrelenting exposure to an enduring stressor such as war, or emotional, physical or sexual abuse.

A significant number of survivors of trauma experience a partial or complete reduction of symptoms over the course of the first several months after the event (Rothbaum, Foa et al. 1992). Therefore, although trauma and/or adversity may increase the risk of a range of psychological disorders, research has consistently confirmed that many people are able to adapt to the experience of a traumatic or adverse event with minimal disruption to their lives. Others eventually recover their psychological functioning after a symptomatic period (Bonanno 2004; Rutter 1985). Moreover, a number of researchers have also noted that traumatic or adverse event(s) may be a precursor to PTSD in some people (Shaw, 2000).

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<sup>&</sup>lt;sup>6</sup> Symptomatic: a symptom of a disease or illness.

## 2.4.2 The Lifetime Prevalence of Trauma and/or Adversity

A number of researchers have observed that most people are exposed to at least one psychologically or physically traumatic event during their lifetime (Pineles, Mostoufi et al. 2011). Other studies have demonstrated that, on average, an individual experiences nearly three traumatic or adverse events during their life (Alim, Feder et al. 2008). Estimates of the rates of trauma worldwide indicate that every year millions of children experience CTA, such as abuse and/or neglect (Norris 1992, Krause 2008). In a retrospective study of over 17,000 adults, Felitti et al. (1998, cited in Little, Akin-Little & Somerville, 2011) reported that more than one-half of the research sample had experienced at least one traumatic and/or adverse event in their childhood, with approximately 25 per cent reporting having experienced two or more types of trauma. In addition, an increasing number of children and adolescents have also been victims of natural disasters, such as Hurricane Katrina in 2005, which displaced more than one million people (Akin-Little & Little, 2008). Read et al. (2005) reviewed 51 studies conducted between 1987 and 2005 and found high rates of childhood sexual and physical abuse among psychotic patients (sexual abuse: 48% of females and 28% of males; physical abuse: 48% of females and 50% of males) (Álvarez, Roura et al. 2011).

# 2.4.3 The Health and Social Effects of CTA

In recent decades common understandings have developed about the relationship between traumatic and adverse life event(s) and consequent psychological, social and health consequences manifested throughout an individual's lifespan (Mueser & Taub, 2008). The exposure to trauma and/or adversity has been associated with increased levels of risk taking and impulsivity, and impaired risk detection. It is also associated with problems with behavioural self-regulation (Butchart, Phinney Harvey et al. 2006, Afifi & MacMillan 2011). Additionally, there is evidence to suggest that CTA is associated with poor physical health outcomes such as heart disease, cancer, lung and liver disease, and skeletal fractures

(Perry & Azad, 1999). CTA has also been linked with increased risk of chronic fatigue, migraines, bladder problems, asthma and diabetes (Goodwin & Stein, 2004).

As I have discussed, in the field of psychosis research there is much debate about the relationship between traumatic life events, particularly CTA, and the development of psychosis (Fritch, Mishkind et al. 2010). Rosenberg et al. (2001) recently reviewed research focusing on psychological trauma in individuals with severe mental illness published from 1970 to 2000. The authors concluded that 'people with severe mental illness have a markedly elevated risk of exposure to trauma' (Rosenberg, Mueser et al. 2002). Specifically, between 34 and 53 per cent report the experience of CTA, while between 43 and 81 per cent also report having experienced some type of victimisation in their life (Read & Ross, 2003). Reported incidences of CTA, particularly physical assault, have been shown to be predictive of the development of psychotic symptoms (Morrison, Frame et al. 2003) and the development of psychotic disorders (Janssen, Krabbendam et al. 2004), with a significant cumulative relationship evident between trauma and psychosis. CTA has also been shown to be more prevalent in schizophrenia populations when compared with the general population (Shevlin, Houston et al. 2008). Additionally, people with a psychotic illness and a history of CTA may have a different clinical presentation at the onset of the illness compared to those with psychotic illnesses and no exposure to CTA (Dvir, Denietolis et al. 2013). This can present challenges for services in identifying CTA within a psychosis population. Despite the increasing evidence to support the association between traumatic and/or adverse life experience(s) and psychotic states and/or symptoms, there is a need for further research that addresses the question of how these two phenomena are linked (Kilcommons & Morrison, 2005).

In a recent review of the research, it was reported that the prevalence of CTA among adults with psychotic disorders greatly exceeds that of the general population (Üçok & Bikmaz, 2007). Furthermore, there is a sound empirical base that has established the links between trauma and/or adversity and the subsequent onset of a number of psychological disorders (Mulvihill, 2005). A number of studies have established that CTA can increase the risk of dysthymia<sup>7</sup> and major depressive disorders (Lizardi, Klein, Ouimette et al., 1995; Ritchie, Jaussent, et al., 2009). For example, Wingo, Fani, Bradley and Ressler (2010) investigated the genetic and environmental risk factors associated with mental illness in a population of urban, low-income, highly traumatised men and women. The researchers established that exposure to CTA was a risk factor for both depression and PTSD. Other research by Schoedl, Costa et al. (1994), explored the concept of 'sensitive periods' following a traumatic experience(s) and found that the timing of this trauma had a significant effect on brain regions undergoing specific increases in growth at the time of the traumatic experience. This research established that females who had experienced sexual abuse between the ages of three and five years evidenced a smaller hippocampal volume in MRI scans when compared with a similar non-trauma cohort. Additionally, the writers determined that adults who were sexually abused in childhood after the age of 12 years were ten times more likely to develop severe symptoms of PTSD compared to those who experienced sexual abuse prior to the age of 12 years. Furthermore, over 30 per cent of children exposed to trauma and/or adversity each year develop PTSD (Mulvihill, 2005). Therefore, the literature suggests that CTA can not only increase the risk of major depressive disorders and PTSD, but can also influence the course of these disorders, including earlier onset, higher levels of psychiatric comorbidity, and higher levels of chronicity (Lizardi, Klein & Ouimette et al., 1995).

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<sup>&</sup>lt;sup>7</sup> Dysthymia: a mild but long-term (chronic) form of depression.

Physical and sexual abuse in childhood has also been associated with numerous physical illnesses in adulthood including the development of liver disease, migraines, respiratory, musculoskeletal, gastrointestinal illnesses, and neurological and gynaecological problems (Norman, Means-Christensen, et al. 2006). The relationship between CTA and substance use is also well established (Wilsnack, Vogeltanz et al. 1997, Dube, Felitti et al. 2003). Additionally, numerous studies have demonstrated that as many as 62 to 81 per cent of adult women in drug treatment services report having experienced some type of childhood abuse and/or neglect (Gil-Rivas, Fiorentine, Anglin & Taylor 1997; Liebschutz et al. 2002; Teets 1995). These frequencies compare to general population rates of 26 to 30 per cent (USA data) (Kendler et al., 2000; MacMillan et al., 2001). It also appears that CTA is associated with the use of alcohol at an earlier age (Arnow, Hart et al. 1999, Dickinson, DeGruy et al. 1999, Norman, Means-Christensen et al. 2006). Alcohol use also has been shown to potentially exacerbate the likelihood of a developing mental illness, including the aforementioned PTSD, as well as hindering the process of psychological recovery (Liebschutz, Savetsky et al. 2002).

## 2.4.3.1 The Psychological Effects of CTA

As I have discussed, although a relatively large percentage of the population experiences some form of trauma and/or adversity in their lives, the majority of individuals exposed to this trauma and/or adversity do not develop mental illness such as PTSD. Large proportions demonstrate evidence of resilience to such experiences (Mancini & Bonanno, 2006). A number of research reviews (e.g. Fergusson & Mullen, 1999) have estimated that approximately a third of all individuals who have experienced CTA will not exhibit psychiatric difficulties in later life. Moreover, McGloin and Widom (2001) found that 48 per cent of children with documented histories of CTA (in this case abuse and/or neglect) did not meet the criteria for adult psychiatric disorders (including depression, anxiety and PTSD), while 38 per cent did not have a history of substance abuse.

Emerging research in neuroscience<sup>8</sup> has demonstrated that CTA is associated with both structural and functional changes in the brain, most notably in the reduction of development of the hippocampus and amygdala, and abnormal frontal-temporal electrical activity (Langeland, Draijer et al. 2004, Evren, Kural et al. 2006). There is also widespread agreement that psychosis occurs in people with a vulnerable predisposition (of a biological or socioeconomic origin) and that onset often follows life events, adverse environments, illicit drug use or periods of isolation. There can be emotional changes and disruptions in cognitive processes of attention, perception or judgement, and at illness onset the most prominent symptoms of delusional beliefs and hallucinations (Garety, Kuipers et al. 2001). While the most significant cognitive deficits are observed in situations of physical abuse accompanied by trauma or neglect, neglect alone has been associated with cognitive deficits in attention, response set and visual-motor integration, but conversely, a greater capacity for problem solving and abstraction (Teicher, Andersen et al. 2002, Teicher, Andersen et al. 2003). Moreover, the developmental influence of CTA on children has been extensively explored. For example, in a review of the literature in the field of CTA by Nolin and Ethier (2007) the authors point out that the deleterious effects of trauma and/or adversity and neglect on the developing child can be twofold: CTA can affect overall child development (Streeck-Fischer & Kolk, 2000) and has been linked with lower levels of IQ (Saltzman, Weems et al. 2006).

### 2.4.4 CTA and Resilience

In exploring the correlation between trauma and/or adversity and resilience, Collishaw et al. (2007) examined successful functioning over a broad range of psychosocial performance domains in adults who had experienced CTA. The researchers noted that 22

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<sup>&</sup>lt;sup>8</sup> Neuroscience: the study of the brain and nervous system, including molecular neuroscience, cellular neuroscience, cognitive neuroscience, psychophysics, computational modeling and diseases of the nervous system.

per cent of their study cohort was classified as psychologically resilient. As previously described, numerous researchers have documented high levels of resilience in children exposed to difficult psychological and economic environments, such as those in which poverty or the experience(s) of maltreatment was present (Bonanno & Mancini, 2008). Recent research has consistently shown that across different types of potentially traumatic events, including bereavement, serious illness and personal attack, up to 50 per cent of people displayed some level of resilience. Nonetheless, researchers caution that exposure to trauma and/or adversity in infancy and childhood can influence a person's ability to represent and understand their own and others' emotions and behaviours. Therefore, CTA can also reduce the ability to cope with and make sense of psychological distress, interpersonal conflict and complex social relationships (Waldron, 2008).

The influence of CTA experience(s) on the development of resilience has also been investigated. For example, Campbell-Sills, Cohan and Stein (2006) concluded that resilience was a mediating factor in reports of CTA (in this sample, childhood emotional neglect) and adult psychiatric symptoms. The researchers found that individuals who reported relatively high levels of emotional neglect during childhood also indicated higher levels of psychiatric symptoms. However, this only occurred in individuals who also demonstrated low levels of resilience. Of note, resilience in this study was determined by utilising several measures of personality, trauma and coping questionnaires, including the Conner-Davidson Resilience Scale measure of resilience (for more discussion of resilience measures for psychosis populations see Chapter 3, section 3.5.10.1). One notable finding from this study was that individuals who experienced significant emotional neglect, but who scored high on personal levels of resilience, also reported low psychiatric symptoms as adults.

Additional factors related to resilience were also identified in the above study. A significant finding was that low neglect/high resilience individuals appeared to be psychologically healthier. The researchers concluded that individuals who experienced trauma and/or adversity but who were able to cope effectively might have experienced additional psychological growth as an outcome of trauma. Secondly, they observed that individuals in the study who displayed resilience in the face of trauma and/or adversity might have represented a highly selective group of 'super-resilient' individuals who were extremely unlikely to develop psychiatric symptoms in adulthood (Campbell-Sills, Cohan & Stein, 2006). These conclusions confirm the large body of research in the field of PTG discussed previously in section 2.2.5.

Indications that the experience of CTA may be a major influence on some individuals' capacity to manage adverse life events successfully incorporates the understanding that the development of resilience is contingent upon a range of complex interrelated mediating factors. For some, the experience(s) of CTA may be one of those influences. Additionally, the way in which an individual understands their CTA experience is associated with whether or not positive psychological health and wellbeing outcomes are achieved. Therefore, those who are able to draw a positive, coherent resolution from difficult or traumatic life experiences may report higher levels of wellbeing (Pears & Fisher 2005, Nolin & Ethier 2007).

## 2.4.5 CTA in Summary

Research evidence has consistently confirmed a relationship between CTA and poor health, psychological and social outcomes in adulthood. This growing body of research into the effects of CTA on psychological functioning continues to develop. However, the literature is not particularly well synthesised across health, psychological and social disciplines (Mulvihill, 2005). While CTA has been linked to a number of poor

psychosocial, health and psychiatric consequences, research has also demonstrated that some individuals can cope and thrive despite those challenging experience(s) (Collishaw, Pickles et al. 2007, Alim, Feder et al. 2008). Although this can be attributed to a range of complex, interrelated health, psychological and social factors, resilience may be an important mediator in this process (Wingo, Wrenn et al. 2010). However, the existence of clear, well-substantiated links between the experiences of CTA and the development of resilience in those individuals who thrive requires further investigation. This is one of my primary intentions in this PhD research.

# 2.5 Recovery

Section 2.5 explores the concept of illness recovery in more depth. I discuss the notion of recovery from mental illness and some of the contested ideas in the recovery field. I consider the recovery concept in the context of mental health service provision in Australia. I examine the implications of recovery philosophy and principles for illness management from a consumer and service perspective.

# 2.5.1 The Concept of Illness Recovery

Recovery from mental illness has become the dominant health practice principle of mental health systems across a number of western countries (Noiseux, St-Cyr et al. 2010). The concept is entrenched in mental health discourse, policy implementation, practice mandates and consumer movements. Recovery principles also define the ways that some mental health clinicians and services engage with consumers about managing their illness and achieving a fulfilling, independent life. The process is described by Anthony as a

deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose

in one's life as one grows beyond the catastrophic effects of mental illness. (Anthony 1993, p.527).

Within an Australian health context, recovery from illness is summarised in the 2003-2008 National Health Plan as:

both a process and an outcome that is essential for promoting hope, wellbeing, and a valued sense of self-determination for people with mental illness. A recovery orientation emphasizes the development of new meaning and purpose for consumers and the ability to pursue personal goals. Mental health service providers should operate within a framework that supports recovery (Australian Health Ministers, 2003).

Australian mental health service practice currently reflects varying interpretations of the recovery construct, ranging from relatively traditional notions of 'clinical recovery' to more progressive understandings about service user self-determination and participation. The latter has gained increasing traction in the practice domains of mental health discourses and clinical service delivery in recent years (Ramon, Shera et al. 2009). Although there are some differing perspectives about the construct, the common principle that underpins mental health services mandates in both the United Kingdom and Australia is that recovery involves reclaiming the right to live a safe, dignified, and personally meaningful and gratifying life in one's community.

Fundamental to the concept of recovery is the understanding that for people with a lifelong mental illness recovery is a continuing process. Consequently the aim of recovery is to develop the capacity of the individual to minimise the negative effects of their illness and achieve a desired quality of life (Roe, Chopra & Rudnick, 2004). Hence, recovery in a contemporary clinical mental health context emphasises self-determination and the usual

life pursuits of education, employment, sexuality, friendships, spirituality and voluntary membership in their communities (Davidson & Roe, 2007).

A wealth of literature based on qualitative research describes illness recovery as taking place in stages or phases. Davidson and Strauss (1992) identified the following four key aspects of recovery in the context of severe mental illness:

[1] discovering the possibility of possessing a more active sense of self, [2] taking stock of strengths and weaknesses and assessing possibilities for change, [3] putting into action some aspects of the self and integrating the results as reflecting one's actual capabilities and, [4] using an enhanced sense of self to provide some refuge to provide a resource against the effects of the illness and (such things as stigma).

A number of frameworks that detail the essential components and processes of recovery have been developed. For example, Wilken (2007) proposes a multidimensional model of recovery that describes the course and outcomes of the process. The model emerged from findings from a meta-analysis of 13 qualitative studies investigating the personal experiences of people who had recovered, or were in the process of recovering, from a serious mental illness. The model distinguishes the following clusters of factors as fundamental to the development of effective recovery-based mental health services:

- recovery as a developmental and self-empowering process over time that progresses from psychological disintegration to stabilisation and reconnection to the community;
- 2. motivation/drives for recovery including understanding, coming to terms with, and gaining control of the illness and its restrictions;

- 3. competences/skills for coping with the illness, including self-care, and the capacity to make independent, meaningful choices;
- 4. social engagement/shifting the social status including being connected to the community in meaningful and productive ways;
- 5. environmental resources: the provision of material, mental health and social support systems required to support the recovery process.

## 2.5.2 Contested Notions of Illness Recovery

The concept of illness recovery is a contested field and this is reflected in a diversity of recovery models and practices (Sayce & Perkins 2000, Dilks, Tasker et al. 2010) and contradictory views about the efficacy of different models of recovery practice (Slade, 2010). Moreover, differences in understanding the process and effectiveness of recovery often exist between mental health professionals/researchers and the population who access mental health services. For example, Davidson (2003) conducted an analysis of published accounts of personal experiences of recovery as part of a larger qualitative investigation. Based on interviews with over 100 people with a diagnosis of psychosis, the study identified common aspects of the experience from a mental health service consumer's perspective as:

redefining self and accepting illness ... overcoming stigma; renewing a sense of hope and commitment; resuming control over and responsibility for one's life; exercising one's citizenship; managing symptoms; being supported by others; and being involved in meaningful activities and expanded social roles. (Davidson 2003, p.45).

Additionally, notions of 'recovery' can vary, including a fundamental difference between the concepts of recovery 'from' illness as opposed to recovery 'in' illness (Davidson, Schmutte, Dinzeo & Andres-Hyman, 2008). Researchers have also noted the difference between 'clinical recovery' and 'social recovery' (Secker, Membrey, Grove & Seebohm,

2008). Moreover, models of recovery have been conceptualised as 'scientific' as opposed to 'consumer' (Bellack, 2006), and 'service-based' compared to 'user-based' in focus (Schrank & Slade, 2007). Acknowledging these opposing positions, Slade (2010) frames illness recovery as characterised by two dimensions. The first is a consumer-based 'understanding' of illness recovery, such as 'personal recovery', which reflects the individually defined nature of the process as experienced by the recovering individual. The second is a clinically focused understanding of recovery, which emphasises the importance of diagnosis, illness symptomatology, social functioning, relapse prevention and risk management. In combining both the process and outcome aspects of the recovery model, Davidson and Roe describe illness recovery as

the amelioration of symptoms and other deficits associated with [a mental illness] to a sufficient degree that they no longer interfere with daily functioning, allowing the person to resume personal, social, and vocational activities within what is considered a normal range. (Davidson & Roe, 2007, p.461)

Given that the construct of illness recovery is a relatively recent development in mental health philosophy and practice, less attention has focused on the role that resilience plays in the recovery process (Bonanno, 2004). While resilience and illness recovery are intrinsically linked, the goal of illness recovery is to assist a person to develop the internal psychological resources (resilience, physical health and coping skills) to achieve independence. However, the connection between the two concepts of resilience and recovery is complicated given there is no universally accepted criterion for 'operationalising' the concept of illness recovery in clinical mental health settings. Given that many mental health services and users use terms such as 'a unique and/or personal journey' to describe the recovery process, confusion remains about notions of 'recovery' as either an outcome or a process (Torrey, Rapp et al. 2005).

In addition, the concept of recovery has received little attention in both practice and research with people who have a severe and persistent mental illness (Anthony, 1993). A number of studies have utilised quantitative and qualitative approaches, including first person accounts, in an attempt to provide a deeper and more comprehensive understanding of the experience of living and coping with a severe mental illness in the context of the recovery philosophy (Roe, Chopra et al. 2004). Nevertheless in the field of mental health it is now widely recognised that people with mental illness can participate actively in their own treatment and become the most significant agents of change. Personal management skills, ranging from greater knowledge of their illness and its treatment to coping skills and relapse prevention strategies, play a critical role in how people recover from mental illnesses (Mueser, Corrigan et al. 2002). Illness recovery discourse and practice play a significant role in defining how illness is considered by mental health services and how the individual manages their own illness.

## 2.5.3 Illness Recovery and this PhD Research

Although resilience is an important aspect of recovery, I distinguish between the two constructs in this study. As I have discussed, recovery for mental illness implies a trajectory in which 'normal' functioning temporarily gives way to threshold or subthreshold psychopathology (e.g., symptoms of depression or post-traumatic stress disorder [PTSD]). This trajectory usually lasts for a period of at least several months before gradually returning to pre-event levels. Full recovery may be relatively rapid or may take as long as one or two years. In contrast, resilience reflects the ability to attain and maintain a stable equilibrium. As I have discussed, resilience has typically been described in relation to protective factors that foster the development of positive outcomes and healthy personality characteristics. This construct has predominantly emerged from research among children exposed to unfavourable or adverse life circumstances (Bonanno, 2004).

Given this, in this thesis I use the notion of recovery in its holistic sense, as suggested by consumer advocates such as Whitley (2014), Australian mental health services, and progressive researchers (e.g. Anthony, 1993). Recovery from illness is defined as an active process of integrating mental health care with daily existence while also creating a purposeful life regardless of diagnosis (Scheyett, DeLuca et al. 2013). This concept of recovery extends beyond traditional notions of 'clinical recovery' (i.e. symptom reduction) to include the service user or consumer's own experiences of their social, psychological, health and economic worlds (Whitley, 2011).

### 2.6 Literature Review- Conclusion

In this literature review I have explored resilience, CTA, psychosis and illness recovery from a range of perspectives. The emergence of the construct of resilience was described. The discussion about resilience was followed by a review of the effects of CTA on psychosocial development and healthy adult functioning. The research evidence linking CTA and psychosis was examined. The third section focused on the aetiology and effects of psychosis. Current understandings of recovery and its application in mental health discourse and clinical praxis were discussed in the final part of the chapter.

The extensive evidence and sound theoretical knowledge that has evolved about resilience during the last thirty years has pointed to its importance for healthy human development and optimum functioning. Although the concept continues to accommodate a wide variety of positions and interpretations, conceptual clarity about resilience is beginning to emerge. In particular, there is an increasing acknowledgement in the field that resilience is a complex, multi-dimensional, environmental and psychological phenomenon. Researchers have concluded that many different paths lead to the development of resilience and that resilient adaptation in the face of trauma and adversity is far more common than previously

believed (Bonanno, 2004). The emphasis on positive adaptability in the context of adversity and trauma is integral to current conceptualisations of resilience.

In this review I also discussed the interplay between mental illness, social disadvantage, poverty and resilience. The research linking trauma and/or adversity in childhood to poor psychosocial and health outcomes including psychosis was examined. This research suggests that trauma and/or adversity is one of a number of complex, interrelated physiological, and environmental factors correlated with the development of psychotic illness. However, literature in the field suggests that resilience may influence an individual's capacity to manage the challenges of living with a psychotic illness. Additionally, there is little clarity regarding the reciprocal effect of CTA and psychosis on resilience development and the specific role of resilience in illness recovery. As resilience appears integral to recovery from mental illness, the principles and practice of recovery concluded the literature review. In each section the rationale for the selection of terminology used to describe CTA, psychosis, resilience and recovery was presented.

In this review I have highlighted that, to date, the conceptualisations of resilience, CTA and psychosis continue to be dominated by a strong focus on biological and genetic factors. These conceptualisations are often positioned within medical and/or psychological paradigms. However, I argue that understandings of resilience can be enhanced by consideration of the reciprocal effects of broader psychological and social contexts that are also intrinsic to determining psychosocial functioning. Hence, I have explored research that investigated the reciprocal effects of psychosis on social and health outcomes. As the relationship between poverty, social disadvantage and psychosis has been well substantiated, the multiple effects of poverty and associated social disadvantage on the development of resilience capacity were also reviewed.

Why CTA is a possible precursor to the development of resilience in some people has not been widely examined, particularly in psychosis populations. This literature review across a number of disciplines and practice fields has established that resilience, psychosis and CTA are complex phenomena. Furthering understanding about the complex effects of CTA on people with a psychotic illness is essential for deepening understandings of human responses to stress and trauma. This has the potential to improve the effectiveness of existing mental health clinical practice with psychosis populations (Wingo, Fani et al. 2010).

In Chapter Three, the methodology applied in this research is described. I discuss the research typology and methods of data collection and a critique of mixed-method research is included. The processes I used to analyse the research data and the challenges that arose during the conduct of the research are discussed.

# Chapter 3

# **Theoretical Framework and Methods**

### 3.1 Introduction

The previous two chapters outlined the research question, aims and rationale. I examined the literature pertaining to the topics under investigation in this research. In this chapter I describe how I conceptualised and conducted the research. I include an overview of the research methodology including a discussion of the quantitative, qualitative and mixed-method research fields. I describe the rationale underpinning the integration of the qualitative and quantitative research paradigms into a mixed-method approach. In addition, I describe the approaches I used to gather, combine and analyse both the quantitative and qualitative data sets. I explore the concept of reflexivity in qualitative research with reflections on the genesis, conduct and outcomes of the research from a personal perspective.

# 3.2 Quantitative and Qualitative Research

When determining the study design for this PhD research, I reviewed the theoretical paradigms defining the qualitative and quantitative research fields in relation to the topics under investigation. Both fields of inquiry have long histories distinguished by competing and divergent world views, systems, methodologies and methods of representation. These position the research ontologically (i.e. its view of reality) and epistemologically (i.e. its view of knowing) (Guba & Lincoln 1994, Heron & Reason 1997). As Miyata and Kai (2009) suggest, the divisions between the long-established traditions of qualitative and quantitative research were once profound, with both fields continuing to maintain their distinctiveness. However, research that applies both traditions into mixed-method designs has gained increasing prominence. In mixed-methods inquiry, qualitative methods are applied to interpret the meaning of the conclusions produced by quantitative methods.

Proponents of mixed-method research argue that it provides more powerful methodological frameworks compared with the singular use of qualitative or quantitative designs, particularly for research in the social sciences.

As Mays and Pope (2000) suggest, quantitative methods in mixed-method designs define the 'what' or the 'extent' of the question under investigation while qualitative methods establish the 'why'. In the context of this PhD research, I regarded quantitative methods as most suited to identifying the specific health, social and economic factors that potentially influence the lived experience of psychosis and/or CTA. I intended that the interpretive research paradigm of qualitative research would capture additional data. This described the unique experiences and insights of participants about living with psychosis, CTA and their understandings of resilience. Using both empirical and interpretive methods to analyse two separate data sets enhanced the breadth, depth and nature of the research evidence. Integrating the findings and conclusions drawn from the combined data sets strengthened the recommendations for future research, policy and praxis in the field of mental health. I therefore determined the methodology for this PhD research by selecting methods that were a 'best fit' for investigating and integrating aspects of a complex research question rather than by a commitment to one particular research paradigm.

# 3.2.1 Quantitative Research

Quantitative research is the empirical investigation of psychological, biological, social or physical phenomena through the application of mathematical, statistical or computational procedures. The primary aim of quantitative investigations is to develop a hypothesis and/or to discover theories across a population that are verifiable (Sandelowski, 2000) and generalisable (Amaratunga, Baldry et al. 2002). The quantitative research field is based on positivism or an objective construct of the world (Howe & Eisenhart, 1990). Human behaviour is seen as able to be categorised and measured using methodologies that employ

a level of deductive logic (Amaratunga, Baldry et al. 2002). Quantitative inquiry is regarded as essential to reducing the influence of multiple variables and to identify cause and effect. This can include controlled experimentation, such as random sampling, blinding, highly structured protocols, and written or orally administered questionnaires with a limited range of predetermined responses.

In quantitative investigations sample sizes are designed to be representative and are generally much larger than those used in qualitative research. This is intended to provide enough data for statistical analysis (Carey, 1993). Studies are evaluated through the application of statistical processes that test the reliability and validity of research. The qualitative approach is often defined in reference to quantitative research methods, with some researchers conceptualising qualitative research as devoid of measurement and less scientific (Patton, 1990). Furthermore, there has been a perception amongst some disciplines that qualitative research is not as authentic and less scientific than quantitative research (Crabtree 1999, Creswell 2009).

As I have discussed, I selected a quantitative methodology for Study One. I accessed the South Australian SHIP data set for Study One. This is part of an Australia-wide research project examining the impact of psychosis on the lives of a large population cohort. Analysis of the South Australian SHIP data set allowed me to identify the significant factors that can determine the health and social status of people with psychosis living in the northern region of South Australia. I supplemented this data with an analysis of demographic data sourced from the Australian Bureau of Statistics (ABS) describing the characteristics of the South Australian SHIP catchment in which the research population resided. Of note, the statistical data analysis and representation of the Study One findings, in the form of numbers and tables, reflects the quantitative view of measurement as an

objective, systematic process concerned with the identification of relationships between variables (Carr, 1994).

The 'snapshot' that emerged from the analysis of both the SHIP and ABS data sets provided the social and health context for a deeper examination of psychosis and CTA. It allowed for the identification and analysis of the relationships between the complex health, economic and social factors that affected the lives of people with a psychosis illness. In addition, it enabled me to extract a representative sample of CTA and non-CTA participants from the SHIP data in order to compare their health and social outcomes. This established the 'what' and 'extent' of the topics being investigated. Exploring the role of resilience in this phenomenon became the question of 'why' investigated in Study Two (Moffatt, White et al. 2006).

The quantitative methods I applied in Study One reflect the positivist view that proposes objective observation and measurement are at the core of scientific endeavours. This views the researcher as able to study a phenomenon without influencing or being influenced by the investigative process (Sale, Lohfeld et al. 2002). However, a consideration for this researcher was how the question of 'why' could be more fully addressed. Giving prominence to the world views, perspectives and understandings that participants attributed to their subjective experiences of psychosis, CTA and resilience had the potential to add richness and depth to the understanding of the research topics. As the empirical methods of quantitative research are not designed to interpret the psychological and social worlds of research participants, I also selected an interpretive design that provided information about participants' experiences of CTA, psychosis and resilience.

### 3.2.2 Qualitative Research

Qualitative research is based on interpretive paradigms. These posit the existence of multiple constructed realities that are influenced by context, time, culture or a combination of all three. Qualitative researchers assume that different realities can be understood through the exploration of individuals' experiences and reflections (Denzin & Lincoln 2000, Tobin & Begley 2004). Methods of inquiry are intentionally designed to provide more insightful information about participants' worlds than the detached methods of the quantitative approach (Aguinaldo, 2012). Researchers in the qualitative field assert that understanding an individual's unique meaning can only be accomplished within a framework that enables the researcher to become immersed in the research setting.

However, criticism of qualitative research has tended to be directed at a perceived lack of rigour in the way that empirical data is collected, measured and represented. Critics posit that these processes fail to create research that is free of bias and subjectivity. For example, Patton asserts that qualitative research remains: 'rife with ambiguities. There are purposeful strategies instead of methodological rules. There are inquiry approaches instead of statistical formulas. Qualitative inquiry seems to work best for people with a high tolerance for ambiguity' (1990, p.183).

Nonetheless, qualitative researchers maintain that, while quantitative research continues to dominate public perceptions about what constitutes 'good science', there is now increased rigour in qualitative inquiry that is advancing the position of qualitative approaches to research (Cheek 2007, Tracy 2010). Criticism regarding lack of rigour in qualitative methods can be attributed to the differences in epistemological assumptions about the nature of knowledge that define each field including the relationship between the knower and what is known.

As Tracy (2010) observes, qualitative researchers reject external evaluation criteria such as validity, objectivity and reliability to evaluate the rigour of research. They view the researcher as subjectively immersed in the research process and not detached from the phenomenon being investigated. Therefore, qualitative research emphasises personal accountability, an ethic of caring and non-coercion, as well as reflexivity. This requires researchers to explore the influence of their unique, often deep-seated personal values, views and conduct on the research process. The concept of reflexivity is central to questions of rigour in qualitative research and I discuss it further in relation to this PhD research in section 3.7. Additionally, Marks and Yardley (2004) describe qualitative methods as providing a means to develop deep insight into the viewpoint of participants. Similarly Duffy (1987) and Carr (1994) suggest that the strength of qualitative inquiry is that its methods allow participants to speak in their own voices. Interpreting participants' personal and complex accounts of their experiences of CTA, psychosis and resilience was central to my research aim of furthering insight into the lived experience of psychosis and CTA. An additional aim of this PhD research is to explore the implications of participants' views, perceptions and understandings of CTA, psychosis and resilience for recovery practice and to examine these perceptions and understandings in the context of the delivery of mental health services.

Some qualitative researchers view quantitative methods as investigating only small aspects of reality and as being unable to generate understanding of whole phenomena (Krauss, 2005). As I have previously stated, these researchers consider that the immersion in the complex world of research participants is essential in order to represent their experiences and perspectives. Therefore, researchers do not approach an investigation with predetermined views about a phenomenon being investigated. These views emerge through the interactions between the researcher and research respondents. Consequently, I collected

the interview data in Study Two through a semi-structured face-to-face interview process with questions serving as prompts to explore participants' individual understandings and lived experiences. This process of meaning making is central to qualitative research. It means that research participants' words define the ideas and themes that emerge from the research and that these inform the findings and contributions of the study. Meaning making requires data collection and analysis methods that include face-to-face interaction, flexible data-gathering strategies, and analysis processes that organise and categorise the data into different levels and forms. These are intended to represent, as accurately as possible, the meanings research participants attribute to the events and experiences of their lives.

In Study Two, the qualitative methods of analysis and interpretation provided scope for participants to contribute to constructing the research findings about psychosis, CTA and resilience. Therefore, the research participants were active co-constructors of knowledge rather than passive objects of the research process. The methods of analysis and interpretation of qualitative research have contributed to descriptions of qualitative research as an evolving or emergent process. However, as Krauss (2005) suggests, qualitative researchers can demonstrate accountability by providing detailed accounts of their data collection and analysis processes for scrutiny and critique. I therefore provide a detailed description of the methods I applied in Study Two in the following sections.

As the researcher, I intended that the analysis of the face-to-face interviews in Study Two would be integrated with the analysis of the broader health and social context of participants. This context was examined in Study One. As I have discussed, in order to fully understand the phenomenon of CTA, psychosis and resilience, I considered it essential to gain insight into the subjective worlds of research participants through face-to-face interaction and qualitative data analysis. However, I also considered that a broad and

deep understanding of the complex phenomena under investigation in this research should extend beyond the subjective worlds of participants. Therefore, it was important to investigate the wider health, social and economic context that influenced participants' lives by using quantitative methods. The dual process of embedding participants' interpretations of their subjective worlds within a broad description and analysis of their external social and health context thus required the integration of both qualitative and quantitative methods into a mixed-method research design.

#### 3.3 Mixed-Method Research

Historically, mixed-method research appeared when the research community was divided into two distinct groups determined by adherence to either quantitative or qualitative methods. Johnson and Onwuegbuzie describe mixed-method research as 'a class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study or set of related studies' (2007).

In recent years, a large volume of literature has emerged that defines the characteristics of mixed-method research. This includes conceptualisations of its methodologies and how these can be applied in complex social and political domains (Miles & Huberman, 1994). The increasing use of mixed-method designs in social research has also been strongly influenced by the development of theoretical models that incorporate the inclusion of research participants' own perspectives. Consequently, mixed-method research is frequently utilised for researching health, psychological and social outcomes (Tashakkori & Creswell, 2008). According to Strauss and Corbin (1990), it is particularly suited for this purpose as it enables the researcher to engage with the complexity of health, health care provision, and the socioeconomic environment in which the research takes place.

In this context, mixed-method research has often been used to identify contextual influences that impact on disparities in the delivery of mental health policy and the dissemination and implementation of evidence-based practices. Pope and Mays (2008) suggest mixed-method research is particularly suited for research in the social sciences when quantitative methodologies are initially applied to gain a general sense of the question under investigation. The theories emerging from these inquiries are then further tested using qualitative methods. Integrating both methodologies in one research project then creates 'a final product which can highlight the significant contributions of both', (Nau, 1995, p.1).

The qualitative method in the mixed-method design has enabled me to investigate the phenomenon of resilience in a CTA sample from the South Australian SHIP cohort. This is integral to the research aims of furthering understanding about how resilience is manifested and its significance in enhancing psychological functioning in people with a psychotic illness. By identifying the social, health and economic factors that impact on the lives of people with psychosis, the mixed-method methodology focuses on the question of 'what has happened'. The mixed-method methodology also provides me with the capacity to explore 'what it means' by identifying the relationship between resilience and CTA and highlighting the significance of resilience to psychological functioning in people with a psychotic illness. As Rossman and Wilson (1994) and Johnson and Onwuegbuzie (2004) suggest, combining the empirical and interpretive research domains can assist in the elaboration and development of analysis by providing scope for richer detail and the development of new ideas and insights about the phenomenon under investigation.

Finally, Palinkas et al. (2011) suggests mixed-method research does not diminish or replace quantitative or qualitative approaches. Rather it draws from the strengths of the

two paradigms and minimises their limitations. Quantitative methods are best suited for the examination of the complex SHIP database including the use of ABS demographic data. Establishing and examining the health, social and community context of participants' lives is central to the aims of this PhD research of furthering understanding of how the recovery from mental illness, CTA and resilience are interrelated. Furthermore, I can explore the findings from the quantitative study in relation to the influence that mental illness has upon poverty and poor health outcomes. In addition, quantitative methods allow me to compare the health and social outcomes of a representative sample of CTA and non-CTA participants and I can discuss these outcomes in the context of their implications for mental health policy and clinical praxis.

## 3.4 Data Analysis

# 3.4.1 Study One: Quantitative Data Analysis

Section 3.4 describes how I applied the mixed-method methodology when combining the distinct data sets of Study One and Study Two. I provide an overview of the quantitative analysis used in Study One to identify the health and psychosocial status of the SHIP cohort. I describe the qualitative method used to investigate resilience in a representative sample of participants with psychosis and CTA and present the processes I applied to combine and analyse the two data sets.

## 3.4.2 SHIP Research Typology<sup>9</sup>

The South Australian SHIP data set provides a detailed statistical profile of the participant cohort for this research. The SHIP research utilised a two-phase design. In Phase One, screening for psychosis took place in public, specialised mental health services, and non-government organisations providing services for people with a mental illness. In Phase Two, people who were screened positive for psychosis in the preceding phase were

<sup>9</sup> Typology: the research or systematic classification of 'types' of groups that have characteristics or traits in common.

randomly selected and stratified by age group (18–34 years and 35–64 years) for assessment and potential interview. Of the 7,955 people across Australia screened positive for psychosis 1825 were interviewed. Four hundred and two SHIP participants were interviewed from the South Australian catchment area.<sup>10</sup>

The SHIP interview schedule consisted of 32 modules including the following domains: psychopathology; substance use; physical health; functioning, disability and quality of life; education, employment and accommodation; and childhood adversity. The social, health and economic profile information of participants consisted of, but was not limited to:

- demographic status;
- socioeconomic and psychosocial status;
- health and physical functioning;
- diagnosis and symptomology.

For a detailed description of the SHIP research typology and discussion of how the SHIP project was implemented in South Australia, see Chapter 4.

## 3.4.2.1 SHIP Psychosocial, Demographic, Diagnostic and Cognitive Assessments

The primary domains covered in the SHIP interview were:

- clinical profile;
- cognitive profile;
- social participation and functioning profiles;
- measures of impairments and disabilities;

-

<sup>&</sup>lt;sup>10</sup> See Chapter 4, Table 4.1a and 4.1b for ABS (2006) demographic information about the South Australian SHIP research cohort.

- socioeconomic profile;
- mental health service utilisation;
- treatment and perceived need for services;
- measures of quality of life.

Diagnostic assessments were addressed utilising the Diagnostic Interview for Psychosis (DIP). This is a semi-structured interview consisting of the 97 items from the Operational Criteria for Psychosis. It uses probes derived and adapted from the World Health Organization Schedules for Clinical Assessment in Neuropsychiatry. Items covered in the DIP included:

- hallucinations;
- depression;
- subjective thought disorder;
- delusions;
- mania.

# 3.4.3 SHIP Statistical Analysis

In Study One I examined the demographic and illness profile of the SHIP cohort (n=391 SHIP research participants), which included comparing the CTA cohort (n=232) and non-CTA cohort (n=159) in relation to the following domains of illness and health:

- demographic profile;
- illness diagnosis;
- health functioning;
- substance use;

- socioeconomic status;
- psychosocial status.

I accessed additional ABS data to provide an overall demographic assessment of the SHIP South Australian catchment.

I used a two-step model-building procedure to determine variables associated with CTA. I initially used univariate analyses (chi-squares and t-tests) to determine relationships between CTA and a range of independent variables. These analyses informed my multivariate approach to explore differences between the CTA and non-CTA cohorts. As the incidence of CTA is much higher in females, I also stratified these analyses by gender to explore gender-specific associations. For a more detailed discussion of the quantitative statistical analysis used for Study One, see Chapter 4.

### 3.4.4 The Identification of CTA

The SHIP interview schedule rated the incidence of CTA using a self-reported item on CTA in the childhood adversity module. CTA identification was made in response to questions referring to socialising, social isolation and social withdrawal (question 9.01). Of the 402 SHIP in the South Australian cohort, 232 self-reported the experience(s) of CTA. This represents 57 per cent of the entire South Australian SHIP cohort.

## 3.5 Study Two: Qualitative Data Collection

The following section provides a detailed account of the process of conducting Study Two. Included is a discussion of the methods used to identify, recruit and interview participants for the face-to-face interviews. A summary of the pilot study for Study Two is included. I also discuss the challenges, ethical considerations and procedures involved in the collection of the qualitative research data.

### 3.5.1 Pilot Study

I conducted a pilot study prior to the commencement of this PhD research. I did this to ensure that the instruments I selected and/or developed for Study Two were best suited to accomplish the research aims. I used this pilot study to develop the instruments for the main study. Thus, I piloted the face-to-face qualitative interview with the primary aim to assess the usability of the interview schedule. I also evaluated three quantitative measures of resilience, intended to provide an assessment of participants' level of resilience as a way of supplementing participants' own self-reports of resilience. I tested both the interview and quantitative resilience measures with 11 volunteer participants.

As a result of this pilot study I made several changes to the face-to-face interview schedule. This included the addition of five extra questions that expanded on the topics of trauma and/or adversity and participants' understandings of resilience. Additionally, following completion of the pilot study, I selected the Resilience Scale (developed by Wagnild & Young, 1993) as the most accessible resilience measure for use with the CTA participant sample in Study Two for the main study (see section 3.8 for further discussion about the selection of resilience measures in the research). I summarise the evaluation of these three quantitative resilience measures in section 3.6. See Appendix 1 and Appendix 2 for the pilot study and main study ethics and participants' information. Appendix 3 is the pilot study interview schedule and Appendix 4 is the main study interview schedule.

Following a review of the interview data from the pilot study and consultation with my research supervisors, I also decided to use data from the pilot interviews to supplement the data collected from the main study. I combined the pilot study data and the main study data, as the pilot study data was similar in content and of sufficient quality not to compromise Study Two.

## 3.5.2 Selection Criteria for Study Two Participants with CTA

I randomly selected Study Two participants from the South Australian SHIP database. For Study Two I only selected those participants who identified as having experienced CTA. All 27 participants in Study Two retained their South Australian SHIP identification number (ID) assigned during the SHIP project. These ID numbers were stored in a password-protected electronic database with the ID numbers linked to the names and contact information of the South Australian SHIP cohort. I have also used these ID numbers to identify participants' responses in the thematic analysis as detailed in Chapter 6. This ensures that I could track participant responses and that the reader was aware that I utilised a cross-section of participants' responses in Study Two.

# 3.5.3 Refusal to Participate

For the main study I posted a total of 87 contact letters and participant information sheets to potential participants. I conducted this mail-out in a series of ten participant invitation letters at a time. I then conducted interviews with those who responded to those ten letters and who indicated a willingness to participate in the research. Following the completion of the initial interviews, I posted an additional ten letters to the next group of potential participants. The purpose of contacting participants in groups of ten was to ensure that I had sufficient time to arrange and conduct interviews and transcribe the data before posting out the next series of ten research contact letters and participant information sheets.

As I have stated, 27 participants in total agreed to participate in a Study Two interview. Of the remaining 60 potential participants who were not interviewed, three had died, while 46 participants were un-contactable. Eleven potential participants declined to be interviewed or self-reported that they were too physically or psychologically unwell to participate. Those who declined to participate did not voice any concerns regarding the aims of the research or identify any other factors that may have influenced their decision not to

engage. However, 12 potential participants did raise issues related to stigma, interview inconvenience, an unwillingness to discuss personal emotional and health topics, and a dislike of research.

# 3.5.4 Study Two Interviews

The 27 face-to-face interviews were conducted between 25 January 2012 and 20 July 2012. I determined interview numbers at the point of theme saturation. Theme saturation is described as occurring when a researcher has: 'the empirical confidence attained from repeatedly comparing data to additional data' (Bowen, 2008, p.28). The January to July 2012 time frame ensured there was sufficient time between each of the interviews to allow for continuing review and comparison of the interview data between each interview. For a copy of the interview schedule for Study Two please see Appendix 4.

Ongoing reviews of the interview process itself were important to informing the evolution of the interview schedule for subsequent interviews. The process of analysis, comparison and critique helped determine the point when theme saturation was reached. At the conclusion of the 23<sup>rd</sup> interview, review of the collected data as well as audit trail entries indicated that no new significant themes were emerging. Therefore, I identified the 27<sup>th</sup> interview as the final interview. No participants were interviewed more than once. However, I recontacted two participants by telephone to clarify several points they had raised during their interviews. This was done following transcription of each interview when I identified a number of discussion points that required further exploration or clarification. In retrospect, interviews could have ceased after the 23<sup>rd</sup> interview. However, at the time, I considered that additional interviews might possibly identify additional themes. Nonetheless, no new themes were identified in the final seven interviews.

Study Two is divided into four distinct but interconnected segments according to the four primary themes that emerged during the Study Two interviews:

- resilience;
- childhood trauma and/or adversity;
- psychosis;
- speculative change and reconciliation.

The four sections also include a number of 'subordinate' themes that explore additional topics raised by participants during the interviews. See Chapter 6 for a more detailed description of the Study Two themes and sub-themes.

## 3.5.5 Interview Scheduling and Location

The Study Two face-to-face interviews were conducted at times chosen by participants. All but one of the interviews took place in the offices of the Northern Adelaide Mental Health Directorate, located in the suburb of Salisbury, South Australia. A single interview took place in the participant's home due to their childcare obligations. While a traditional clinical mental health setting may not be considered conducive to personal comfort or emotional candidness the majority of participants appeared familiar and comfortable within the interview location. This may be attributed to their ongoing attendance at the location for clinical mental health services and a familiarity with the service and its location.

### 3.5.6 Note Taking

Given that all Study Two participants gave their permission for interviews to be electronically recorded, there was limited need for note taking during the interviews. Any note taking was restricted to short summaries that pertained to issues or questions that

required additional prompts or follow-up during the course of the interview. This enabled me to devote my full attention to participants' responses and to construct relevant follow-up prompts while concentrating on the progression and content of the interview.

# 3.5.7 Audit Trail

To ensure that the methodological approach had integrity, I maintained an audit trail. An audit trail is used 'primarily by the investigator as a means of tracking the evolving analysis and monitoring personal responses, or are to be presented in their entirety to a research auditor for more formal review and assessment of confirmability, dependability and credibility' (Lincoln & Guba 1985, Rodgers & Cowles 1993). The audit trail provides a record of the ongoing research process and insights into the theoretical, methodological and analytical choices made by the researcher (Bowen, 2008). The entries facilitate concurrent analysis, act as a tool to aid any changes to the interview schedule, guide the emergent themes, and provide prompts for subsequent interviews. At the conclusion of each interview, I documented my initial reflections about the interview including possible emerging themes and areas where I could improve or expand upon an interview technique. During the transcription process, I documented details of significant changes in the emotional and physical status of participants including voice tone, gestures, body movements, expressive gestures, as well as any significant interruptions during the interviews. This ensured that a representation of the true meaning of the participant's account was documented (Gillham, 2005). This phase of the process also aided in the interpretation of the data. I also used the audit trail to document my reflexive thoughts (I discuss reflexivity further in section 3.7).

Additionally, I maintained a record of the various recruitment issues and challenges I experienced during the data collection phase. This ensured that an accurate catalogue of some of the successes and challenges experienced during the data collection process was

maintained. For example, I documented at the conclusion of each interview some of my interpretations of the interview content, how participants were engaged in the interview process, and if any points of concern needed to be raised with the participant post-interview. Additionally, I maintained a notebook that documented the decisions I made during the transcript coding and data analysis process. This included documenting a number of challenges and complexities with coding some of the interview content. I entered data into a Microsoft Excel spreadsheet to maintain all participant contact and basic demographic information to manage contact dates and other relevant information. Furthermore, I maintained several Microsoft Word documents detailing the specific coding of text from the transcripts. I utilised these throughout the various stages of the thematic analysis as a record of my process and progress.

# 3.5.8 Study Two Interviews in Practice

The Queen Elizabeth Hospital Human Research Ethics Committee and the University of Adelaide Ethics Committee granted ethics approval for Study Two. Following this ethics approval, I informed eligible individuals about the research via postal mail after randomised selection from the CTA cohort of the SHIP participants. Each participant was invited to participate in a face-to-face interview. Interviews were semi-structured, in-depth, and ranged in length from approximately 45 to 70 minutes. Interview participants determined the length of the interview. I planned the interview to be relatively informal yet remain topic focused so as to elicit as much meaningful data as possible within the given time frame (Gillham, 2005). I considered this method an appropriate way of generating information-rich data while the semi-structured nature of the interview process allowed the participants to shape the direction of the interview. This provided opportunity for me to ask the pre-determined questions, to clarify certain points, and to probe deeper if needed.

Before commencement of the interview, I reiterated the objectives of the research to the participant, reassured them of their confidentiality and anonymity, and clarified their right not to answer questions if they felt uncomfortable. I informed participants that they could withdraw from the interview at any stage. I also sought permission to record interviews electronically and all participants gave their permission for me to do so. I then provided the opportunity for participants to ask any questions they had about their involvement in the research. Following clarification of questions or concerns, I provided a copy of the Participant Information Sheet and Consent Form (see Appendix 2) and again extended an invitation to ask questions. If a participant did not have any questions and stated their willingness to participate in the research I asked them to sign a copy of the Consent Form. I provided each participant with one copy to keep for his or her own record while I retained the original signed copy.

Rather than adhering to a strict structure, I intentionally kept the Study Two interview schedule broad. This provided the scope for participants to elaborate and reflect on their own experiences, insights and perceptions. I developed the interview schedule with openended questions, some prompts and several additional follow-up questions. I intended the schedule design to elicit as broad a range and depth of participant responses as possible (Breakwell, Hammond et al. 2000). Given the interviews' semi-structured format, I did not consider it appropriate for me to base the analysis of participant responses upon sole quantification of the data. Therefore, I did not document how many participants discussed their specific experience(s) or type(s) of CTA (this data was collated separately from the SHIP data set in Study One). This was because I did not consider that the reporting of the nature of participants' CTA experience(s) was relevant to the purpose of Study Two. Rather, the focus of Study Two was on how participants contextualised and articulated their CTA experience(s) and their interpretations of resilience in the context of psychosis.

# 3.5.9 Data Transcription

On completion of the interviews, I transcribed all of the recordings. During this process I utilised a transcription process recommended by Hammersley (2010). That is, I documented an exact account of all verbal expressions, and in some cases observations, such as reflective pauses, laughing and joking. This process familiarised me with the content and type of interview data and assisted in the identification of preliminary themes.

From my perspective as the researcher I considered it important that the transcribed data retain all the information needed to identify possible themes and that it represented an accurate reflection of the nature and content of the interview (Braun & Clarke, 2006). Scrutinising the interview data during the transcription process also enabled me to develop an insight into the emerging themes. It allowed me the opportunity to conceptualise what was significant in the data and consider the topics and themes that may require further exploration. I excluded all identifying participant information from interview transcripts.

# 3.5.10 Measures of Resilience

This section provides a summary of the Resilience Scale. The Resilience Scale is the sole quantitative measure of resilience used in this PhD research. I applied this measure as I deemed it important to utilise a quantitative measure of resilience to provide additional rigour to the study of resilience, particularly in the context of how participants self-reported resilience during the face-to-face interviews. As I have discussed, in Study Two I asked participants about their understandings about resilience and to evaluate their own resilience in the context of their experience of psychosis and CTA. My intention was to corroborate participants' insights from the face-to-face interviews about their resilience and compare these personal assessments with a quantitative resilience measure.

#### 3.5.10.1 The Resilience Scale

As I have stated, the Resilience Scale I selected for use in Study Two was developed by Wagnild and Young (1990). This measure is based on personal competence and the acceptance of self and life as determinants of resilience. The degree of resilience is measured with a 25-item scale using a 7-point rating ranging from 1 (disagree) to 7 (agree). Wagnild and Young (1993) assert that a psychometric evaluation of the scale demonstrates its internal consistency, reliability and concurrent validity. Although originally tested with adult participants, some studies have confirmed the suitability of the measure with people of different ages and ethnic groups (Ahern, Kiehl et al. 2006). An overall resilience score is determined by totalling all items. Possible scores range from 25 to 175, with higher scores reflecting higher levels of resilience.

In order to confirm that the Resilience Scale was the most suitable measure for use in this PhD research, I compared it with other similar resilience measures. As I have stated, I asked participants in the pilot study to complete and evaluate an example of each of the following:

- Resilience Scale (Wagnild & Young 1993);
- The Ego-Resiliency Scales (Block & Kremen 1996);
- Resilience Assessment Questionnaire.

I asked five brief questions regarding the format, style and understanding of the intent of the questions to determine:

- Which of the three questionnaires was the easiest to complete?
- Which questionnaire was the easiest to understand?

- Which questionnaire did they prefer the most?
- Were there any questions that the participant was unable to understand?
- Additional comments about the efficacy and accessibility of the questionnaires.

I provided participants with a copy of each instrument and asked them to follow the instructions and then complete the measures independently. I observed participants complete the scales and, following the interview phase, I reviewed participants' perceptions of the accessibility and feasibility of each resilience measure. This resulted in a positive response to the Resilience Scale. This was because participants believed the Resilience Scale was more accessible, had a manageable number of questions, and had an easy format/layout. Accessibility and ease of use was the highest priority for participants, with several unable or unwilling to complete either or both of the other two resilience measures available. The Ego-Resiliency Scales was assessed as being difficult to understand, while the Resilience Assessment Questionnaire was considered either overly long or too 'wordy'. I administered all of the resilience scales at the conclusion of each interview and I randomised the order of the measures at each pilot interview to ensure that no measure was favoured. As a result of these pilot interviews, I chose the Resilience Scale as the resilience measure suitable for use in the PhD research. Please see Appendix 5 for a reproduction of the Resilience Scale, Appendix 6 for the Ego Resilience Measure and Appendix 7 for the Resilience Questionnaire.

# 3.5.10.2 Suitability of the Resilience Scale

The Resilience Scale as used in Study Two is a resilience measure developed for broad population use only. As I discuss in greater detail in Chapters 4 and 8, there were some benefits in using the Resilience Scale. However, there were also some challenges. I anticipated that a quantitative measure of resilience would strengthen the reliability of participants' self-reports of their own levels of resilience. However, the Resilience Scale is

a relatively generic 'off the shelf' psychological scale and one not specifically tailored to particular cohorts (i.e. psychosis populations). During administration of the measure it became clear that it was not sufficiently nuanced in its design or content to measure resilience in this population group accurately. Participants were not consistently able to contextualise or understand the questions and some voiced frustration at having to participate in this aspect of the interview. Given this, the Resilience Scale may not be the most appropriate tool for the measurement of resilience in a psychosis population. For more analysis and discussion of the Resilience Scale data in this PhD research, see Chapters 4, 5 and 8.

# 3.6 Qualitative Data Analysis

This section provides an account of the data collection and interpretation process of Study Two. I describe how I became familiar with the content of the data, how I categorised it thematically, and some of the challenges that arose during this process.

# 3.6.1 Study Two Qualitative Data

The aim of the thematic analysis generated from the Study Two interviews is to provide a nuanced and detailed account of the themes that emerged from the interview data. I referenced these themes directly to the research topics. The process of thematic analysis comprises the identification of themes through 'careful reading and re-reading of the data' in order to develop insights into the phenomena of CTA, psychosis and resilience (Rice & Ezzy, 1999). It encompasses the development of a data coding system and the linking of codes or units of data to form overarching categories or themes. The process is adapted from Lacey and Luff (2001) and encompasses the following procedures:

- familiarising oneself with the data through review, reading, listening and so on;
- transcribing audio recorded material;

- organising and indexing the data for easy retrieval and identification;
- anonymising the face-to-face interview data;
- coding or indexing the data;
- identifying themes;
- re-coding the themes;
- developing provisional categories;
- exploring relationships between categories;
- refining themes and categories;
- developing theories related to the data and incorporating pre-existing knowledge;
- testing theory against the data;
- thesis writing, including excerpts from the original data (i.e. quotations from the Study Two participant interviews).

This process does not generally occur in a linear sequence as the stages listed above can sometimes overlap. Data analysis thus occurred continuously throughout the data collection process. While I was in progress, I documented and observed how personal meanings were created and what might influence those meanings. I viewed a single theme as a device that captured an idea or concept vital in the identification of a pattern of meaning representing the narratives of the participant group.

In order to identify the most meaningful data, the coding of the data included recognising these important moments and encoding these moments prior to the process of interpreting their meaning (Boyatzis, 1998). For example, if a participant discussed their perceptions or insights about resilience (e.g. 'it's nature verses nurture isn't it?' [1140]), I 'saw' a comment such as this as an important moment or insight. I then coded this example under

the theme of 'resilience' for later interpretation. I conducted this process with every participant interview and with every line of text in the interview transcript.

Deciding upon the number and the type of themes was a multifaceted, emergent process. My initial attempts to develop a thematic framework generated a larger number of themes than I initially anticipated. After some additional re-reading and review of the pilot transcripts and the audit trail entries, I refined the thematic frameworks further to reflect the complexity of the subject matter and the range and diversity of participant responses. This period of thematic refinement included a series of discussions regarding theme development with my research supervisors. Professor Cherrie Galletly played an important role in helping to define the research context and providing the guidance I needed to conduct the research. Dr Lana Zannettino was instrumental in supporting me through the complex processes of developing the themes and in ensuring the thematic analysis reflected the health, psychological and social context of the research. This input was significant in clarifying my thinking about the efficacy of the themes and ensured that I maintained a focused approach encompassing strict adherence to the original research aims and objectives.

Developing and refining the thematic framework proved to be a continuous process. It occurred concurrently throughout the familiarisation and indexing stage, when ideas about themes were either reinforced or abandoned. Throughout the thematic analysis process I remained cognisant of the need to maintain a critical stance about the research, as recommended by Miles and Huberman (1994). Therefore, I continuously reviewed the interview data for discrepancies, maintained quality checks, and critically evaluated the veracity of conclusions and theories emerging from the analysis.

#### 3.6.2 Data Familiarisation

Following completion of the interview process, I became immersed in the data. I transcribed the audio recordings of each interview and listened to them numerous times. I reviewed my post-interview observational notes, reflections and all the summary information from the audit trail. Undertaking this process ensured that I developed a detailed understanding of the data. This allowed me to cultivate a sense of the key ideas and emerging themes. I utilised NVivo 9 software (QSR International, Sydney, Australia) to assist in the identification and the categorisation of the primary themes. I considered and coded each line, sentence and paragraph of the interview transcripts as potential themes to identify the major themes, corresponding variations and sub-themes. During this process a conceptual framework emerged. When organising the data into themes I provided a title for each theme and took direct excerpts from the interview transcripts to introduce the content of each theme as suggested by Breakwell, Hammond et al. (2000). This strategy provided a sense of the thematic construct of the research and demonstrated how participant responses directed and defined the focus of the study.

# 3.6.3 Indexing the Interview Data

I itemised a list of recurring themes and ideas by drawing on the social, health and psychological context of the research and the interview data. Once I had generated this initial list, I constructed a 'conceptual framework' or 'index'. When reviewing this data I sought out themes that were substantive and revealed attitudes, insights, behaviours, motivations or points of view. I completed the process of applying each of the thematic frameworks to all of the data electronically. I then used NVivo 9 to apply theme headings to corresponding text, which I found to be an efficient way of completing the indexing process. The NVivo 9 software allows users to apply more than one theme heading to a corresponding piece of text. This facility was particularly beneficial as a piece of text could be interpreted as evidence of a number of different themes. I consequently categorised the

NVivo 9 codes into the final four primary themes and the corresponding sub-themes. I regarded these themes as providing the most significant insight into participants' own interpretations of their psychosis, CTA, resilience, illness recovery, and their health and social condition. I then consolidated each one of the four overarching themes and corresponding sub-themes to form a hierarchical structure (see Figure 3.1).

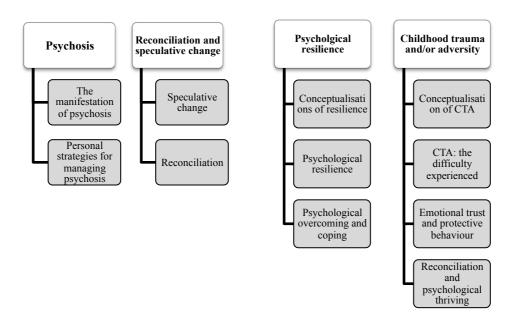


Figure 3.1: The thematic structure of the Study Two interview data

# 3.6.4 Theme Saturation

Interview numbers were determined when either data replication or redundancy was evident (i.e. theme saturation). To reach this point I continuously invited new participants for interviews until data had been amassed 'to the point of diminishing returns, when nothing new is being added' (Bowen, 2008). As I discussed in section 3.5.3, it became apparent at the completion of approximately 23 interviews that no new themes were emerging from the interview data. However, due to some slight variability in the interview content and in an attempt to ensure that no new potential themes would emerge, I conducted an additional four interviews.

#### 3.6.5 Ethical Considerations

This research was conducted with approval from the relevant ethics bodies. The ethics approval process consisted of an ethics application for the pilot research phase, followed by the primary research project. I initially sought approval for the pilot research from the Queen Elizabeth Hospital Human Research Ethics Committee in November 2011. On 25 November 2011, the research project was provisionally approved pending minor changes to participant information letters and consent forms. The approval identification number for the pilot research was 2011143.

Full approval for the pilot research was obtained on 10 January 2012. Following this approval, the University of Adelaide's Research Ethics Committee also approved the pilot research as this involved the same sample of participants. I sought approval for Study Two on 23 February 2012. Approval was granted by the Queen Elizabeth Hospital Human Research Ethics Committee following some minor amendments to participant documentation. The approval identification number for Study Two was 2012042. Following this approval, the University of Adelaide's Research Ethics Committee also approved the research.

Qualitative research utilising in-depth interviewing as a method of collecting information from participants, particularly if they are psychologically or socially vulnerable, raises ethical and practical concerns (Walls, Parahoo et al. 2010). As I previously noted, I had developed an understanding of the mental health service structure, personnel and programs in the northern region of Adelaide through my clinical practice and role as a mental health researcher. Therefore, any ethical or practical issues that may have arisen during the interviews could be promptly addressed to minimise any discomfort for research participants. If a participant were to voice any personal concerns, I had the capacity to

forward these concerns onto a caseworker or other identified health professional/support worker. If a participant had indicated during the interview that they might harm themselves or others, I would have informed them that I was ethically mandated to disclose any information about their risk to the relevant care provider. Despite these precautions, no Study Two participants raised any issues about the research, nor was I required to contact mental health workers with concerns about participants' mental states.

I was not required to undertake any consultation with participant case mangers or their carers. Participants in Study Two were given the option of having a family member or friend present. They were informed at initial contact that they were not required to make an immediate decision to participate in the research and that they were welcome to discuss their involvement with others. None chose to do so. If participants did not wish to make a decision immediately, I contacted them again at a pre-arranged date to discuss their potential involvement in the research. Interviewees were remunerated for their participation in the interview for their time and travel costs to the amount of 20 dollars per participant.

## 3.7 Reflexivity in Research

In this section I explore the concept of reflexivity introduced at the beginning of this chapter. During the research process I documented the reflexive process described here in a personal journal as part of the audit trail. I have condensed it into the following reflexive summary.

In the qualitative research field reflexivity is posited as a method to 'legitimise, validate, and question research practices and representations' (Pillow, 2003, p.175). The concept of reflexivity is central to questions of rigour in qualitative research. Reflexivity is grounded in the premise that the biographically and socially situated researcher is part of a research

community that has distinct perspectives and traditions (Angen, 2000). These form the views that underlie the conceptualisation of the research and the interpretation and representation of findings. Reflexivity requires researchers to be transparent about their world views and theoretical foundations formed by their history, gender, and ethnic and cultural influences. It includes being clear about their role, motivation and qualifications for exploration in the field (Mauthner & Doucet, 2003).

# 3.7.1 Issues of Perspective

As with all research, the choice of topic and the theoretical foundations that defined this study were influenced by my experiences, values, and social and cultural past. This also influenced the way I positioned the research topics within a social and health context.

As the researcher I am an Anglo-Saxon male raised in a professional family in the inner suburbs of Adelaide, South Australia. I experienced a relatively privileged childhood that provided security, opportunity and exposure to strong perspectives about the role of political, economic and social systems in creating a just and equal society. I spent my post-school years travelling and working in a variety of fields, including on an assembly line in a large car manufacturing plant. These experiences provided me with an insight into how labour systems function. These experiences also allowed me to observe firsthand who benefited from and controlled work conditions and deepened my awareness about the forces that maintain social and economic disadvantage. These experiences deepened my understanding about how economic and social structures privilege some individuals and groups while constraining others.

My undergraduate studies shaped my consciousness about social and health issues related to mental health in low SES communities. My honours dissertation, titled *I am ADHD: The experience of adolescents diagnosed with ADHD and their families living in Adelaide's* 

northern suburbs, examined the social construct of health and psychosocial functioning in young people living in the northern suburbs of Adelaide, South Australia. I conducted this research in the secondary school system, which enabled me to observe how the institutional structures and cultures of high schools can inadvertently alienate and marginalise adolescents and their families in low SES communities.

Following my undergraduate studies, I was employed for five years as a mental health clinician with the South Australian public mental health service. This was followed by the role of research coordinator in South Australia for SHIP, located within the Northern Adelaide Local Area Network mental health service. Through these experiences I became acutely aware that people with psychosis often experience levels of poverty and social isolation that are significantly higher than those of the general population. I also observed how the daily challenges of living in poverty were related to poor physical health, social isolation and reduced participation in educational and employment opportunities. I came to understand that the reasons for this are highly complex. This led to my conviction that I needed to explore the research topic for my PhD project through a broad health and social perspective that included due consideration of the range of complex, interacting factors that affect health, poverty and social outcomes for this population.

In my clinical mental health and research roles with SHIP, I was conscious of the challenges involved in integrating government health policy and service delivery responses to address needs within disadvantaged communities. As a mental health clinician and SHIP research coordinator working in a large and complex public health organisation, I observed how political and social systems could often be self-perpetuating and resistant to change regardless of internal and external influences. Consequently, the importance I place on advocacy to improve the focus on mental health is evident in this PhD research. This

includes calls for more integrated and coordinated services, evidence-based practice and workforce development.

In the light of my own world view, I found that I needed to be continuously vigilant about ensuring that the advocacy position in this research was evidence-based. My previous work as a mental health clinician encompassed a significant client advocacy role. However, as a member of a large statutory organisation, I was also aware of the constraints that hindered the ability of services to support recovery for people with a mental illness. Participants' responses in Study Two dealing with service responsiveness demonstrated that underresourced services in disadvantaged communities make it difficult for these services to meet the complex needs of people with a psychotic illness and experience(s) of CTA. These findings provided further evidence that supported an advocacy position for improvement in mental health service delivery and system support.

#### 3.7.2 Questions of Participant Voice

My intention as a researcher was to recognise that participants are autonomous, enable them to impart personal insights and information freely during the interview process and listen to their voices (Orb, Eisenhauer et al. 2001). However, I am also aware that I am representing the views of participants from a researcher's position of authority and privilege and that this may have influenced my interpretations of their responses. Additionally, although I had not worked in a clinical mental health capacity with any of the research participants, my previous clinical role afforded me statutory authority that may have impacted on participants' responses during the interviews.

Moreover, the psychological vulnerability of some of the research participants, together with the sensitive psychological nature of the research focus, may have magnified the power differential that can exist between research participants and researchers. However,

my awareness of the power differentials inherent within the participant–researcher relationship was in itself an important element in attempting to address and reduce this power differential. Furthermore, I acknowledge that the nature of the research process undertaken predominantly positions participants as those who are 'studied' and the researcher as the 'expert' investigator. Consequently, the research process limited the role of participants in the interpretation of the data and the construction of the recommendations. I realise that this process is contrary to my clinical mental health commitment to the mandate of recovery practice that seeks to work with people to create a mutual understanding of their illness and their role in the recovery process.

I resolved these tensions by returning to the broad aims of this PhD research, the outcomes of which are to improve the lives of people with psychosis. This confirmed that research and clinical practice might have different methods in attempting to achieve similar aims and outcomes. I also ensured that the interviews were conducted in a manner that was flexible, open and honest, so that participants had maximum opportunity to give voice to their experiences and perspectives. Moreover, discussion with my research supervisors about how power can shape the relationship between the researcher and research participants led me to conclude that it is not possible to fully resolve all of the issues of voice. Instead I concluded that such issues can never be fully resolved as they are part of the emergent and somewhat 'messy' processes of research.

#### 3.7.3 Issues of Research Relevance

In addition, questions relating to the relevance of the PhD research became increasingly apparent as the study progressed. In my previous role as the South Australian SHIP site coordinator I had developed an insight into the potential of research to delineate issues, redefine policy agendas and reform practice. These insights reinforced my views about the power of knowledge to transform policy and practice in relation to complex social issues.

However, I have also long been aware of the disconnection between the knowledge developed by researchers and the application of such knowledge by mental health clinicians. When I reflected on this issue from a practitioner's perspective, I recalled that a great deal of research does not point to clear clinical implications. Additionally, research knowledge can be perceived as inaccessible and consequently disregarded by clinicians and consumers alike. As a practitioner, I had personal insight into how the day-to-day demands of clinical work and the limited opportunities for professional learning can prevent ongoing engagement with new research. Conversely, as a researcher, I was aware of the expectations and demands placed on the research community that often result in the publication of research that only speaks to academic or research audiences. Consequently, I had to balance questions about the need for clinical relevance, accessibility and portability of this research against the need to fulfil the formal requirements of a PhD research project.

#### 3.7.4 Matters of Research Depth

As the PhD research progressed I also questioned whether it would be of sufficient depth to expand on already well-established understandings of the topics of psychosis, CTA and resilience. Investigating this complex phenomenon within a health and social context required me to review the theoretical paradigms, discourses and practices of a range of disciplines, cultures, and statutory and non-statutory work environments. The multidisciplinary focus that defines mental health service provision in the catchment from which the South Australian SHIP research cohort is derived became an increasingly strong factor as the research progressed. Consequently, I considered concepts that underlie medical, allied health praxis and community development studies, and that permeate the disciplines of psychology and sociology, when framing the health and social focus of this PhD research.

Additionally, the supervisory panel for this PhD research represents an interdisciplinary perspective. As a mental health clinician I am committed to multidisciplinary collaboration despite experiencing some of the service challenges this can entail. This commitment to multidisciplinary collaboration is based on my understanding that multiple factors and systems contribute to the aetiology of mental illness and that effective service provision requires professionals from different disciplines to contribute their knowledge and expertise to enhance service quality. However, I have also observed that multidisciplinary collaboration can often result in the discipline with the highest status dominating the decision-making process. Moreover, a multidisciplinary approach can also result in a broad and uncoordinated clinical focus that can ultimately compromise consumer recovery. I am therefore aware that, in relation to this PhD research, too broad a focus could limit the potential of the research to deepen the knowledge base in specific discipline fields. Conversely, too narrow a focus could potentially limit the development of deeper understandings about the research topics and hinder discussion about their practice implications within multidisciplinary settings. Therefore, I had to review the research constantly to ensure it was maintaining focus, depth and coherence in view of the complex, multilayered questions and topics I was investigating.

#### 3.8 Conclusion

I have presented a summary of the quantitative, qualitative and mixed-method research fields in this chapter. I outlined the conceptualisation of the research and its underlying theoretical and value-based position. This includes the rationale underpinning the integration of both qualitative and quantitative paradigms into a mixed-method approach. In the following chapter I present the results and discussion of Study One. In Chapter 5 I consolidate the discussion undertaken in Chapter 4 in a reproduction of a submitted journal paper about the physical and psychological manifestation of CTA in psychosis populations. In Chapter 6 I present the results and the discussion of Study Two.

# Chapter 4

# **Study One**

#### 4.1 Introduction

As I have discussed, this research investigates resilience and the influence that the experience(s) of CTA may have on the development and manifestation of resilience in a psychosis cohort. As I highlighted in Chapter 3, the use of a mixed-method framework has enabled me both to analyse the SHIP participant data quantitatively while also qualitatively exploring participants' personal understandings and insights about the effects of CTA and psychosis upon their lives utilising a thematic analysis approach. Consequently, this chapter describes Study One. It is an overview of the South Australian SHIP research data and includes a quantitative analysis of the effect of CTA in a psychosis cohort. Study One provides a broad overview of the health, social and economic condition in which the South Australian SHIP research participants reside. I also include ABS demographic data in this chapter to provide a broader social and economic context.

As I have stated, Study One is the quantitative thematic analysis of the South Australian SHIP data, while Study Two is an analysis of face-to-face interview data, with a specific focus on resilience, CTA and the personal understandings of the lived experience of psychosis. The insights and perceptions from Study Two focus solely on the qualitative data collected from 27 randomly selected participants who had experienced CTA.

# 4.1.2 The Quantitative and Qualitative Context

As I discussed in Chapter 3, mixed-method research has been criticised in some academic and research circles by 'purist' methodologists as not providing sufficient rigour and precision for serious analytical research (Johnson & Onwuegbuzie, 2004). Nonetheless, I have selected a mixed methodology for this PhD research as the most appropriate approach

for the following reasons. First, by analysing the South Australian SHIP quantitative data it is possible to generate a broad demographic assessment of the health and social domains of the cohort, including their psychosocial, illness and vocational status. Secondly, when the quantitative SHIP data analysis from Study One is combined with the interpretive focus of the qualitative data from Study Two, the two data sets allow for examination of a range of complex psychological and social phenomena. The two data sets provide scope to examine CTA in a health, psychological and socioeconomic context and to explore the manifestation of resilience in psychosis recovery. Thus, the combination of the quantitative and qualitative data sets also enables me to explore broad medical, psychological and social insights and perceptions that I can use to inform the discussion section in Chapter 6 as well as the findings and recommendations as discussed in Chapter 8.

Research has established the psychological and social foundations of resilience (Bonanno 2004, Cicchetti 2010) and how the pathways that link trauma and/or adversity with health outcomes can span the emotional, behavioural, social, cognitive and biological domains (Bonanno & Mancini, 2008). Nonetheless, a deeper understanding of the effects of CTA on the development of resilience may be important to developing better clinical and psychosocial services for individuals, potentially resulting in better health and socioeconomic outcomes for consumers. By quantitatively examining the South Australian SHIP data, a comparison between the CTA and non-CTA groups may help to inform and influence health and social discourses and practice outcomes.

# 4.1.3 Aims of Study One

My intention in Study One was to highlight the health and socio-demographic status of SHIP participants and to quantitatively investigate the relationships between CTA and health and social outcomes. I conducted this quantitative analysis with due consideration to the health and social research focus of this PhD research project. I will also consider some

of the previous assumptions in the research literature regarding deficits in social, health and psychological functioning of people who have experienced CTA and consider how these assumptions may be challenged in the delivery of mental health services.

As I highlighted in Chapter 1, I anticipated that mental illness and comorbid diagnoses within the SHIP cohort would indicate that psychosis, anxiety, depression and substance use would be more prevalent in the CTA-positive cohort. I also anticipated that the CTA cohort might also indicate lower socioeconomic functioning and higher rates of social dysfunction than the non-CTA cohort. These assumptions were based on the weight of evidence in the CTA literature that indicate relationships between CTA and lower socioeconomic, health and psychosocial functioning compared with non-CTA populations.

# 4.2 Study One: Quantitative Analysis of the SHIP Data

# **4.2.1 Study One Context**

The overall SHIP data set includes demographic information about the South Australian SHIP cohort. This data presents important information on socioeconomic status, health, illness, living circumstances, income, family status, physical health and functioning. As I have discussed, it also provides me with the opportunity to explore any potential differences between the CTA and non-CTA groups in the domains of health, psychological and socioeconomic functioning. This comparison allows me to assess the impact and influence of CTA upon resilience, including psychosocial functioning and illness recovery. I present my analysis of the SHIP data in tables, with each table detailing specific psychological, health or economic measures of social functioning. The analysis of the Study One data is followed by a discussion of the results.

## 4.2.2 Study One Method

The SHIP research project was a national psychosis study, which included South Australia (see Chapter 3 for a broader discussion of the SHIP project). The participant inclusion criteria for the SHIP study were people aged 18–64 years who were residents in the South Australian SHIP catchment area, and in contact with designated services such as public specialised mental health services (inpatient, outpatient, ambulatory or community mental health services). These services also included several non-government organisations (NGOs) funded to support people with mental illness and which operated in the South Australian SHIP catchment area. All public mental health services in the catchment area participated in the screening of eligible participants for the South Australian SHIP catchment. Relevant NGOs located in each catchment area were also asked to participate; however in South Australia all mental health consumers are required to be engaged with government health services before accessing additional NGO support. Thus, while 86 per cent of centres and sections within these agencies took part in other Australian catchments (Morgan, Waterreus et al. 2012), this was not applicable for the South Australian SHIP catchment as all NGO consumers were already accessing government mental health services.

# 4.2.2.1 SHIP Research Design

For the SHIP research a two-phase design was employed (Pickles, Dunn et al. 1995) for the SHIP research project. This design was appropriate for estimating the prevalence of a relatively uncommon disorder and was regarded as efficient in identifying those likely to meet diagnostic psychosis criteria for which the full interview schedule was relevant.

In Phase 1, screening for psychosis took place in public specialised mental health services.

A screening instrument was utilised to identify potential participants in the SHIP project.

The Psychosis Screen (PS) is a brief screening questionnaire to classify people who have

been diagnosed with a psychotic disorder (schizophrenia, schizoaffective disorder, affective disorder with psychotic features, delusional disorder, psychosis due to substance or alcohol abuse, organic brain disease, or general medical disease). The screening questionnaire was developed for the first national psychosis survey originally conducted in 1997 (Jablensky, McGrath et al. 2000).

The Phase 1 screening identified three mutually exclusive groups:

- 1. people in contact with public mental health services in the census month;
- 2. people not in contact with these services in the census month but in contact with NGOs supporting people with mental illnesses in that month;
- 3. people not in contact with public mental health services or NGOs in the census month but in contact with public mental health services in the 11 months prior to the census (see Figure 4.1) (Morgan, Waterreus et al. 2012).

The SHIP census month was March 2010.

In Phase 2, potential participants who were screened positive for psychosis in Phase 1 were then randomly selected and stratified by age group (18–34 years and 35–64 years) for interview and assessment.

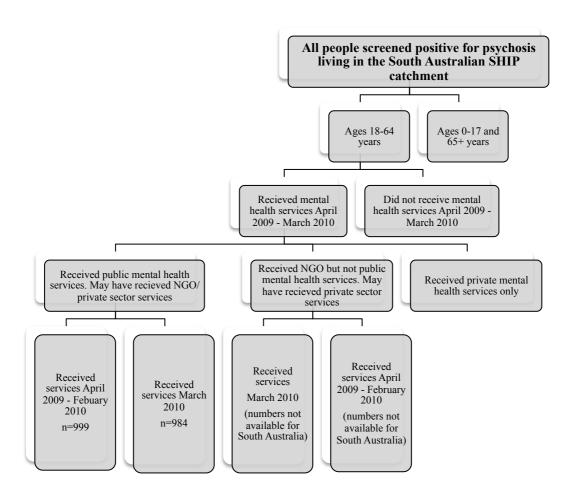


Figure 4.1: Phase 1 – South Australia SHIP Census Enumeration

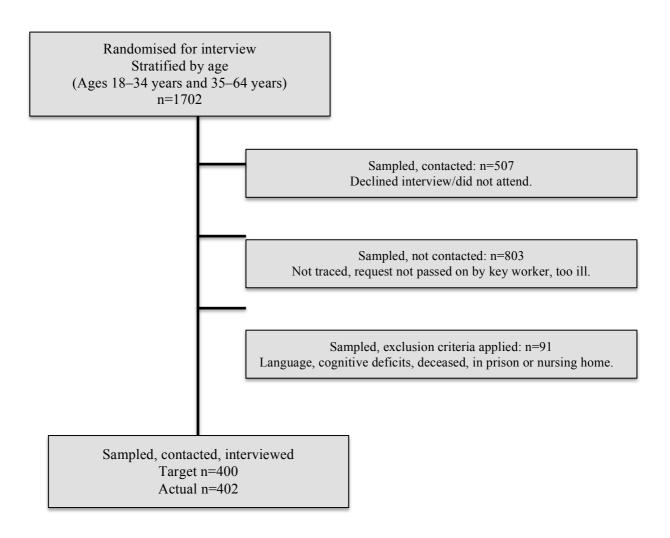


Figure 4.2: Phase 2 – South Australia SHIP Sampling and Interviewing

# 4.2.2.2 South Australian SHIP Study Sample

As I have discussed, the data for this PhD research was collected from the Second Australian Survey of Psychosis 2010 research project (Morgan, Waterreus et al. 2012). The appropriate institutional ethics committees approved the SHIP study and all participants in the South Australian catchment gave written informed consent. Further information regarding the method of the Second Australian Survey of Psychosis 2010 is detailed in Morgan et al. (2013).

The PS identified 1702 adults aged 18-64 years who were residents in the South Australian postcodes identified for the survey. These potential participants had been in

contact with public mental health services in the 12 months prior to the survey and attempts were made to recruit all of these potential participants. Eight hundred and three were unable to be contacted, 16 were known to have died, 33 did not meet inclusion criteria due to an inability to communicate sufficiently in English, 42 did not have capacity to give informed consent, and 507 refused (see Figure 4.2).

The Australian Bureau of Statistics (ABS) data from Table 4.3 indicates that the socioeconomic status of the northern Adelaide region is predominantly low to middle income, with higher concentrations of people with multiple and compound disadvantage compared with the national average. The level of unemployment in the community is higher than that of the Adelaide metropolitan region, while the labour force participation rate is below that of the remainder of the South Australia region. Following the 2006 census, the region's SEIFA<sup>11</sup> Index of Relative Socio-Economic Disadvantage (IRSD) score is 913, below the average for Adelaide and Australia (both 1000).

# 4.2.2.3 SHIP Measures and Assessments

The SHIP interview schedule consisted of 32 modules and included the following domains:

- psychopathology;
- substance use;
- physical health;
- functioning (social, occupational, self-care);
- disability;
- quality of life;
- education;

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<sup>&</sup>lt;sup>11</sup> SEIFA: Socio-Economic Indexes for Areas.

- employment;
- accommodation;
- service use.

Four experienced mental health professionals were seconded from public mental health services as research assistants and conducted all of the South Australian SHIP interviews. The interviewers were trained in the face-to-face administration of the SHIP survey instruments and the collection of standardised physical measures. This included specialised training in administering and scoring the diagnostic interview and assessing global functioning. Inter-rater reliability was assessed during the course of the interviews (Morgan, Waterreus et al. 2012).

Diagnoses were made using the Diagnostic Interview for Psychosis (DIP) (Castle, Jablensky et al. 2006). The DIP contains selected interview questions and probes from the WHO Schedules for Clinical Assessment in Neuropsychiatry (Wing, Babor et al. 1990) mapped onto the 90 diagnostic items of the operational criteria checklist for psychotic and affective illness (McGuffin, Farmer et al. 1991). The DIP measures both lifetime and current illness symptoms for psychosis. A computer algorithm provided the diagnostic classification in accordance with ICD-10, DSM-IV and other criteria on the basis of the DIP scores. This reduced the subjective bias in the interpretation of symptoms and signs (Shah, Mackinnon et al. 2014).

A number of externally developed instruments were used in their entirety for the SHIP interview instrument. These were:

- Assessment of Quality of Life (Hawthorne, Richardson et al. 1999);
- Alcohol Use Disorders Identification Test (Babor, Higgins-Biddle et al. 2001);

- CAGE (Mayfield, McLeod et al. 1974);
- Fagerstrom Test for Nicotine Dependence (Heatherton, Kozlowski et al. 1991);
- International Physical Activity Questionnaire (short format) (Craig, Marshall et al. 2003);
- Multidimensional Scale of Independent Functioning (Jaeger, Berns et al. 2003);
- Personal and Social Performance Scale (Morosini, Magliano et al. 2000).

Items of the Carpenter deficits syndrome from the World Health Organization Schedules for Clinical Assessment in Neuropsychiatry (Kirkpatrick, Buchanan et al. 1989, World Health Organization 1999) were also included (Morgan, Waterreus et al. 2012).

For the purpose of comparing the potential variables between the CTA-positive and non-CTA-positive cohorts in Study One, I have extracted specific items from the South Australian SHIP data that examine:

- Demographic status including
  - gender;
  - o marital status;
  - o parenting and number of children;
  - o education;
  - housing.
- Socioeconomic and psychosocial functioning including
  - employment;
  - o social and family relationships;
  - o social activities;
  - crime and offending;

- o CTA.
- Illness and health including
  - o illness diagnosis;
    - illness onset;
    - duration of illness;
    - life course of illness;
  - o physical health and status;
  - o current and lifetime symptomatology;
  - o suicide ideation;
  - o substance use (tobacco, alcohol, drugs);
  - o functioning and quality of life;
  - o hospital and clinical service engagement.

# 4.2.2.4 Functioning

The level of psychological, socioeconomic and vocational functioning in SHIP participants was determined using the Multidimensional Scale of Independent Functioning (Jaeger, Berns et al. 2003). This instrument assesses the role performance of participants across multiple domains, such as paid and unpaid work, study, and activities of daily living, for the four weeks prior to the interview. The scale also produces a measure of global independent functioning reflecting the overall level of disability, with functioning rated relative to community norms. As this scale does not provide a measure of social functioning, the SHIP interviewers rated this independently for the preceding 12 months. The Assessment of Quality of Life (AQoL) instrument was used to measure health-related quality of life and is a descriptive system for a multi-attribute utility instrument. The AQol measures five dimensions of life: illness, independent living, social relationships, physical senses and psychological wellbeing (Hawthorne, Richardson et al. 1999).

# 4.2.2.5 Physical Health

All South Australian SHIP participants underwent a physical health assessment during the interview. These physical assessments evaluated BMI, blood pressure, high-density lipoproteins, triglycerides and glucose (Galletly, Foley et al. 2012). Measures for metabolic syndrome were defined using harmonised criteria (Alberti, Eckel et al. 2009). The World Health Organization body mass index reference range (World Health Organization 1997) was used to classify participants as underweight (BMI < 18.5), normal (BMI 18.5–24.9), overweight (BMI 25.0–29.9) or obese (BMI ≥ 30). Level of physical activity was assessed using the International Physical Activity Questionnaire (Craig, 2003). Participants fasted overnight (a minimum of 8 hours) prior to the SHIP interview and then provided venous blood samples for measurement of plasma glucose, triglyceride, HDL-C and total concentrations of cholesterol. These analyses were undertaken by standard methods in an accredited pathology laboratory located in the South Australian SHIP catchment area. Participants were also asked if they had a history of high blood pressure, high cholesterol, diabetes, or if they had been informed that their blood sugars were high.

# 4.2.2.6 Socioeconomic Status

The socioeconomic status of SHIP participants was determined at the postcode level using the Index of Relative Socio-Economic Disadvantage, as derived by the Australian Bureau of Statistics using principal components analysis of ABS census data.

# 4.2.2.7 Alcohol, Drugs and Smoking

Lifetime smoking status was determined by asking participants whether they had ever regularly smoked cigarettes, tobacco, cigars or a pipe. Current rate of smoking was defined as self-reported smoking in the four weeks prior to the SHIP interview. Assessments utilised the Alcohol Use Disorders Identification Test (Babor, Higgins-Biddle et al. 2001); the CAGE (Mayfield, McLeod et al. 1974), and the Fagerstrom Test for Nicotine Dependence (Heatherton, Kozlowski et al. 1991);

# 4.2.2.8 ABS and the SHIP Catchment Demographic Information

Table 4.1a and 4.1b detail the demographic characteristics of the SHIP catchment based on data derived from the Australian Bureau of Statistics (ABS). For comparison, national demographic data has also been included in this table. These data sets utilise Estimated Resident Population (ERP) information based on 2006 population estimates determined by the ABS. The ABS data set was extracted from the ABS 2006 database CData<sup>12</sup> 2006, utilising local council boundaries.

# 4.2.2.9 Data Analysis

The Analyses I performed utilised Stata, version 12 (StataCorp. 2011. Stata Statistical Software: Release 12. College Station, TX: StataCorp LP). I used a two-step model-building procedure was used to determine variables associated with CTA. In the first step, univariate analyses (chi-squares and t-tests) were utilised to examine relationships between CTA and independent variables. The second step used multivariate logistic regressions, including only variables that were significantly associated with CTA status at  $\alpha \le 0.05$  in the first step. As the incidence of CTA was much higher in females, the analyses were also stratified by gender to explore gender specific associations.

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<sup>&</sup>lt;sup>12</sup> CData: online tool combining information on Australian society from the 2006 census, with web-based graphing and mapping capability.

# 4.3 Study One Results

# 4.3.1 The Demographic, Social and Economic Status of the South Australian SHIP Cohort

Tables 4.1a, 4.1b and 4.1c detail the social demographic information of the entire South Australian SHIP catchment taken from the 2006 ABS census data. The northern suburbs of Adelaide in South Australia comprise 226,654 residents in a community located across 814 square kilometres. The region comprises the large urban catchments of Salisbury, Playford, Gawler and Tea Tree Gully.

The socioeconomic status of the South Australian SHIP catchment is diverse. The catchments of Salisbury and Playford comprise low- to middle-income households, with higher concentrations of the community with multiple and compound social and economic disadvantage. The catchment of Tea Tree Gully has a higher rate of home ownership than Salisbury and Gawler, and the Index of Education and Occupation indicates a higher level of income and employment than the other catchments.

When compared with national demographic information, the South Australian catchment matches many of the health, economic and social domains of the rest of the country. The population age structure almost equals the national figures, with a slightly higher younger demographic (0–17 years) and slightly lower aged population (65 years and older). Rates of single-parent families are higher than the national average; unemployment is higher while labour force participation is slightly lower. Qualifications beyond high school are substantially lower than the national average (56.2% vs. 45.6%).

Table 4.1a: The Socio-Economic Indexes for Areas (SEIFA) demographic information

	SHIP catchment: South Australia	National figures
Estimated Resident Population (ERP) aged 18-64 (n) (a)	226654	-
Females aged 18-64 (%) (b)	50.3	-
Area (square kilometres)	814.7	-
Population density (total population per km <sup>2</sup> )	432.4	-
Population aged 0–17 (%) Population aged 18–64 (%) Population aged 65 years and over (%)	25.0 62.8 12.2	24.0 62.7 13.3
Other characteristics (b) Indigenous persons (all ages) (%) Australian-born (all ages) (%) Language spoken at home English only (all ages) (%)	1.6 70.7 83.7	2.3 70.9 78.5
Marital status (15 years and over) (b) Never married (%)	32.3	33.2
Family structure (b) One-parent family (%) Couple family without children (%) Couple family with children (%) Other family (%) Total (%)	18.8 35.7 44.2 1.3 100	15.8 37.2 45.3 1.7 100
Employment status (15 years and over) (b) Employed (%) Unemployed (%) Not in labour force / Not stated (%) Total (%)	56.5 3.4 40.1 100	57.2 3.2 39.6 100
Median income (15 years and over) (b)	428.2	466.3
Same usual residence (b) One year ago (%) Five years ago (%)	81.3 55.2	77.3 49.6

Table 4.1b: The Socio-Economic Indexes for Areas (SEIFA) demographic information cont.

	SHIP catchment:	National figures	
	South Australia		
Private, occupied dwellings by tenure type (b)			
Fully owned (%)	28.9	32.6	
Being purchased (%)	40.9	32.2	
Being rented (%)	23.3	26.1	
Other / not stated (%)	6.9	9.1	
Total (%)	100	100	
Persons by dwelling type (b)			
Separate house (%)	89.5	81.2	
Semi-detached, terrace, townhouse (%)	7.3	7.5	
Flat, unit, apartment (%)	2.7	9.9	
Other / not stated (%)	0.4	1.3	
Total (%)	100	100	
Educational attainment (18 to 64 years) (b) (c)			
No post-school qualification (%)	56.2	45.6	
Post-school qualification (%)	33.7	42.7	
Index of Relative Socio-Economic Disadvantage (e)	962.7		
(weighted index score and range for each catchment)	567-1150		
Index of Relative Socio-Economic Advantage and Disadvantage (e)	941.1		
(weighted index score and range for each catchment)	653–1134	_	
Index of Economic Resources (e)	968.1		
(weighted index score and range for each catchment)	611–1184	_	
Index of Education and Occupation (e)	924.8		
(weighted index score and range for each catchment)	736–1116	_	

Table 4.1c: The Socio-Economic Indexes for Areas (SEIFA) demographic information

Northern Adelaide Catchment Areas:	Salisbury	Playford	Gawler	Tea Tree Gully	Catchment totals	National figures
Estimated Resident Population (ERP) aged 18–64 (a)	118,422	70,011	18,913	95,971	272,548	-
Females (%)	50.2	50.4	51.8	50.9	50.8	-
Area (square kilometres)	161	346	213	96	816	-
Population density (persons aged 18–64 per km²)	772.8	208.4	472.2	999		-
Other characteristics (b)						
Population aged 0–14 (%)	20.8	23.4	19.5	19.3	20.7	21.6
Population aged 65 years and over (%)	11.1	12.3	17.0	12.0	13.1	12.1
Indigenous (%)	1.7	2.6	1.2	0.7	105	2.0
Australian-born (%)	68.1	70.8	81.3	73.0	73.3	73.9
Never married (%)	33.7	35.6	29.6	29.0	31.9	30.6
Private, occupied dwellings by tenure type (b)						
Fully owned	27.5	22.1	31.4	34.4	28.8	40.4
Being purchased	42.0	39.1	36.8	43.4	40.3	26.7
Being rented	23.7	31.8	25.7	16.8	24.5	26.7
Other	0.7	0.5	0.9	1.4	0.8	6.3
TOTAL private, occupied dwellings	93.9	93.5	94.8	96.0	94.5	100.0
Persons by dwelling type (b)						
Separate house	80.0	84.7	82.6	89.9	84.3	82.2
Semi-detached, terrace, townhouse	15.6	9.1	9.2	6.9	10.2	6.2
Flat, unit, apartment	3.8	5.3	6.9	3.1	4.7	8.4
Other (caravan, tent, flat attached to shop etc.)	0.6	0.4	1.2	0.0	0.5	1.5
Not stated	0.1	0.5	0.0	0.0	0.15	1.7
TOTAL persons	100.0	100.0	100.0	100.0	100.0	100.0
Index of Education and Occupation (mean and range) (d)	894	856	951	-	-	960 (731–1271)
Postcodes including at least one rural CD (%) (e)	0.0%	0.0%	0.0%	0.0%	0.0%	68.5%

<sup>(</sup>a) Estimated Resident population (ERP) data for 30 June 2009 were extracted by the Australian Bureau of Statistics (ABS).

<sup>(</sup>b) Census data (2006) for the catchment areas were extracted by the ABS using catchment area postcodes.

<sup>(</sup>c) 'No post-school qualification' refers to no educational attainment or only school-level completion. 'Post-school qualification' refers to certificate, diploma, a bachelor degree, or a graduate or postgraduate level qualification. The percentages do not add up to 100% as persons who did not state their educational attainment levels were not included.

<sup>(</sup>d) Remoteness area data were extracted by the ABS and are based on the Australian Standard Geographical Classification (ASGC). (e) The Socio-Economic Indexes for Areas (SEIFA) were extracted by the ABS using catchment area postcodes to obtain postal area level indexes. The higher the score, the more positive the catchment profile. For example, the higher the Index of Relative Socio-Economic Disadvantage, the less disadvantaged the catchment area.

# 4.3.1.1 Prevalence of Childhood Trauma

Of the 391 participants who provided a response on the CTA question, 232 (59.3%) self-identified the experience(s) of CTA, while 159 SHIP participants did not. Females reported CTA more often than males (χ2=19.7, df=1, p<0.001). Table 4.2 displays the types of CTA experienced in the SHIP cohort. Child sexual abuse (CSA) and abuse/neglect were the most commonly reported childhood traumas. CTA, including CSA, was reported more by females than males, while abuse and neglect were similar across both genders. Conversely, more males than females experienced bullying.

Table 4.2: Types of abuse as identified by SHIP participants

		sample 232)	Male (n=114)		Female (n=118)	
CTA type	n	%	n	%	n	%
Child sexual abuse (CSA)	69	29.7	16	14.0	53	44.9
Abuse/neglect	62	26.7	31	27.2	31	26.3
Bullied	17	7.3	12	10.5	5	4.2
External experience of death <sup>13</sup>	15	6.5	11	9.7	4	3.4
Accident/injury	11	4.7	7	6.1	4	3.4
Poor health	7	3.0	3	2.6	4	3.4
Domestic violence	6	2.6	5	4.4	1	0.9
Parental divorce/separation	6	2.6	4	3.5	2	1.7
Other <sup>14</sup>	39	16.8	25	21.9	14	11.9

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<sup>&</sup>lt;sup>13</sup> External experience of death: death of a family member/friend.

<sup>&</sup>lt;sup>14</sup> Other: social isolation and loneliness, family alcohol and drug use, or unspecified trauma.

#### 4.3.1.2 Sample characteristics

Table 4.3 presents socio-demographic characteristics for the CTA group (n=232) and non-CTA group (n=159), and the total sample (n=391). More women reported experience(s) of CTA ( $\chi$ 2=19.7, df=1, p<0.001) than men. More of the non-CTA group reported that they were currently not in a relationship ( $\chi$ 2=6.0, df=1, p=0.012); further analyses found that women who had experienced CTA were more likely to be married or in a de facto relationship ( $\chi$ 2=7.1, df=1, p=0.023). There were no significant differences in the relationship status of the CTA and non-CTA males. More of the CTA cohort had children ( $\chi$ 2=6.0, df=1, p=0.013) and, in those providing care for their children, 20 per cent exhibited signs of obvious or severe dysfunction in the quality of their childcare. Significantly fewer of the CTA positive cohort received disability support than might have been expected ( $\chi$ 2=4.0, df=1, p=0.046). However, the two groups did not significantly differ by age, education or employment.

Table 4.3: Basic socio-demographic characteristics of the CTA group, non-CTA group and whole cohort

		CTA		CTA		otal	
	(n=	=232)	(n=	=159)	(n=	=391)	р
Age and sex							
Female (n, %)	118	50.9	45	28.3	163	41.7	< 0.001
Age (mean±SD)	39.1	10.2	37.5	11.1	38.4	10.5	0.16
Marital status (n, %)							
Single	106	45.7	102	84.6	208	53.2	0.001
Married/de facto	59	25.4	24	15.1	83	21.2	
Currently separated, divorced, widowed	67	28.9	33	20.8	100	25.5	
Parenting (n, %)							
Has children	117	50.4	60	37.7	177	45.3	0.013
Children u/18 at home	70	57.4	38	63.3	108	59.3	0.44
Income (n, %)							
Main income source: pension	212	91.8	147	93.0	359	92.3	0.65
Received disability pension	169	79.7	129	87.8	298	83.0	0.046
Received financial help (past 12 months)	40	17.2	38	23.9	78	20.0	0.11
Education (n, %)							
Completed Year 12	43	18.6	41	26.1	84	21.7	0.08
Post-school qualification	102	44.0	69	43.4	171	43.7	0.91
Employment (n, %)							
Paid employment (past year)	54	23.3	38	23.9	92	23.5	0.89
Paid employment (past week)	38	16.4	25	15.7	63	16.1	0.86
Voluntary/unpaid work (past 12 months)	34	14.7	20	12.6	54	13.8	0.56

# 4.3.1.3 Psychological and Physical Health

Table 4.4a indicates that the largest portion of the 232 participants who had experienced CTA met criteria for an ICD-10 diagnosis of schizoaffective disorder (34.5%), while 25.9 per cent had been diagnosed with schizophrenia. This observation was reversed in the non-CTA group, where 40 per cent screened positive for schizophrenia, and 27.2 per cent were diagnosed with schizoaffective disorder. While there were no significant differences in ICD-10 diagnoses between the CTA and non-CTA groups in males, more females with a history of CTA than expected were diagnosed with schizoaffective disorder ( $\chi$ 2=11.1, df=5, p=0.049).

Table 4.4a: ICD-10 diagnosis for CTA and non-CTA groups, stratified by gender

	C	ГΑ	No	CTA	To	otal	
	(n=	232)	(n=	159)	(n=	391)	р
ICD-10 diagnosis (n, %)							
Schizophrenia	60	25.9	63	40.0	123	31.5	0.09
Schizoaffective	80	34.5	43	27.2	123	31.5	
Bipolar, mania	45	19.4	22	13.9	67	17.2	
Depressive psychosis	12	5.2	6	3.8	18	4.6	
Delusional and other non- organic psychoses	14	6.0	9	5.7	23	5.9	
Severe depression	21	9.1	15	9.5	36	9.2	
Males							
Schizophrenia	44	38.6	49	43.4	93	41.0	0.93
Schizoaffective	35	30.7	30	26.6	65	28.6	
Bipolar, mania	13	11.4	15	13.3	28	12.3	
Depressive psychosis	5	4.4	5	4.4	10	4.4	
Delusional and other non- organic psychoses	7	6.1	7	6.2	14	6.2	
Severe depression	10	8.8	7	6.2	17	7.5	
Females							
Schizophrenia	16	13.6	14	31.1	30	18.4	0.049
Schizoaffective	45	38.1	13	28.9	58	35.6	
Bipolar, mania	32	27.1	7	15.6	39	23.9	
Depressive psychosis	7	5.9	1	2.2	8	4.9	
Delusional and other non- organic psychoses	7	5.9	2	4.4	9	5.5	
Severe depression	11	9.3	8	17.8	19	11.7	

While there were no significant differences between the CTA and non-CTA groups on age of psychosis onset (Table 4.4b), the CTA group did report significantly longer mean duration of illness when compared to the non-CTA group (t=2.01, df=389, p=0.043), and were significantly more likely to report a history of suicidality ( $\chi$ 2=4.92, df=1, p=0.026).

Table 4.4b: Age of onset, duration of illness and suicidality for CTA and non-CTA groups, stratified by gender

	_	CTA (n=232)		No CTA		Total	
	(n=2	232)	(n=1	159)	(n=.	391)	p
Onset and duration							
(mean±SD)							
Age of onset	23.8	8.5	24.3	7.9	24.0	8.3	0.55
Duration (years)	15.3	10.0	13.2	9.4	14.4	9.8	0.043
Suicide attempt (n, %)	119	51.3	63	39.9	182	46.7	0.026
Males							
Age of onset	23.0	7.9	23.8	7.2	23.4	7.6	0.45
Duration (years)	14.8	9.1	13.6	8.9	14.2	9.0	0.30
Suicide attempt (n, %)	53	46.5	40	35.4	93	41.0	0.09
Females							
Age of onset	23.8	8.5	24.3	7.9	24.0	8.3	0.55
Duration (years)	12.4	10.9	12.4	10.9	14.8	10.9	0.08
Suicide attempt (n, %)	66	55.9	23	51.1	89	54.6	0.58

Table 4.4c: Key symptoms: Lifetime

	СТ	'Α	No CTA	4	То		
	(n=2)	232)	(n=159	)	(n=3)	391)	p
Lifetime symptoms (n, %)							
Delusions	213	91.8	148 9		361	92.3	0.64
Hallucinations	194	83.6	135 8		329	84.1	0.73
Subjective thought disorder	159	68.5	94 5	9.1 2	253	64.7	0.06
Depressed mood	212	91.4	130 8	1.8	342	87.5	0.005
Anhedonia	203	87.5	115 7	2.3	318	81.3	< 0.001
Suicidal ideation	171	73.7	105 6	6.0	276	70.6	0.10
Poor concentration	179	77.2	107 6	7.3	286	73.2	0.031
Irritable mood	87	37.5	55 3	4.6	142	36.3	0.56
Elevated mood	110	47.4	57 3	5.9	167	42.7	0.023
Lack of insight	47	20.3	49 3	0.8	96	24.6	0.017
Males (n, %)							
Delusions	105	92.1			210	92.1	1.00
Hallucinations	95	83.3	99 8	6.8	194	85.1	0.46
Subjective thought disorder	83	72.8	69 6	0.5	152	66.7	0.049
Depressed mood	98	86.0	91 7	9.8	189	82.9	0.22
Anhedonia	95	83.3	76 6	6.7	171	75.0	0.004
Suicidal ideation	84	73.7	76 6	6.7	160	70.2	0.25
Poor concentration	77	67.5	73 6	4.0	150	65.8	0.58
Irritable mood	35	30.7	36 3	1.6	71	31.1	0.89
Elevated mood	44	38.6	40 3	5.1	84	36.8	0.58
Lack of insight	26	22.8	38 3	3.3	64	28.1	0.08
Females (n, %)							
Delusions	108	91.5			151	92.6	0.38
Hallucinations	99	83.9	36 8	0.0	135	82.8	0.56
Subjective thought disorder	76	64.4	25 5	5.6	101	62.0	0.30
Depressed mood	114	96.6	39 8	6.7	153	93.9	0.018
Anhedonia	108	91.5			147	90.2	0.35
Suicidal ideation	87	73.7	29 6	4.4	116	71.2	0.24
Poor concentration	102	86.4	34 7	5.6	136	83.4	0.10
Irritable mood	52	44.1	19 4	2.2	71	43.6	0.83
Elevated mood	66	55.9	17 3	7.8	83	50.9	0.038
Lack of insight	21	17.8	11 2	4.4	32	19.6	0.34

The CTA-positive group experienced different rates of lifetime symptoms than the non-CTA group (Table 4.4c). For example, the CTA group were more likely to report a lifetime history of depressive mood ( $\chi$ 2=7.96, df=1, p=0.005), anhedonia<sup>15</sup> ( $\chi$ 2=14.30, df=1, p=0.001), poor concentration ( $\chi$ 2=4.67, df=1, p=.031) and elevated mood ( $\chi$ 2=5.16, df=1, p=0.023). However the non-CTA group were more likely to report a lack of insight ( $\chi$ 2=5.68, df=1, p=0.017). Males with CTA also were more likely to have experienced anhedonia ( $\chi$ 2=8.44, df=1, p=0.004) and subjective thought disorder ( $\chi$ 2=3.87, df=1,

<sup>&</sup>lt;sup>15</sup> The inability to experience pleasure.

p=0.049). Conversely, females with CTA were more likely to have reported depressive mood symptoms ( $\chi$ 2=5.59, df=1, p=0.018) and elevated mood symptoms ( $\chi$ 2=4.30, df=1, p=0.038).

Table 4.4d: Experience of key lifetime symptoms for CTA and non-CTA groups, stratified by gender

	СТ	Ά	No CTA	To	otal	
	(n=2)	232)	(n=159)	(n=	391)	p
Current symptoms (n, %)						
Delusions	115	49.6	66 41.	5 181	46.3	0.12
Hallucinations	95	41.0	57 35.	9 152	38.9	0.31
Subjective thought disorder	87	37.5	41 25.	8 128	32.7	0.015
Depressed mood	72	31.0	31 19.	5 103	26.30	0.011
Anhedonia	64	27.6	28 17.	6 92	23.5	0.022
Suicidal ideation	29	12.5	23 14.	5 52	13.3	0.57
Poor concentration	73	31.5	32 20.	1 105	26.9	0.013
Irritable mood	16	6.9	5 3.1	21	5.37	0.11
Elevated mood	23	9.9	4 2.5	27	6.9	0.005
Males (n, %)						
Delusions	62	54.4	46 40.		47.4	0.034
Hallucinations	54	47.4	40 35.		41.2	0.06
Subjective thought disorder	43	37.7	30 26.	3 73	32.0	0.07
Depressed mood	33	29.0	19 16.	7 52	22.8	0.03
Anhedonia	28	24.6	16 14.	0 44	19.3	0.044
Suicidal ideation	13	11.4	14 12.	3 27	11.8	0.84
Poor concentration	30	26.3	19 16.	7 49	21.5	0.08
Irritable mood	5	4.4	3 2.6	8	3.5	0.47
Elevated mood	7	6.1	0 0.0	7	3.1	0.007
Females (n, %)						
Delusions	53	44.9	20 44.		44.8	0.96
Hallucinations	41	34.8	17 37.		35.6	0.72
Subjective thought disorder	44	37.3	11 24.	4 55	33.7	0.12
Depressed mood	39	33.1	12 26.	7 51	31.3	0.43
Anhedonia	36	30.5	12 26.	7 48	29.5	0.63
Suicidal ideation	16	13.6	9 20.		15.3	0.31
Poor concentration	43	36.4	13 28.	9 56	34.4	0.36
Irritable mood	11	9.3	2 4.4	13	8.0	0.30
Elevated mood	16	13.6	4 8.9	20	12.3	0.42

Table 4.5a indicates that 75.2 per cent of the South Australian SHIP participant group were either overweight or obese. The proportion of CTA and non-CTA participants who were overweight or obese were similar (76.8% vs. 75.2%), and there were no significant gender differences between the CTA and non-CTA groups across BMI categories. Additionally,

while not significantly different, the mean BMI score in both the CTA and non-CTA groups (30.9 vs. 29.4) demonstrates the level of obesity in the sample.

Table 4.5a: Body mass index (BMI) for CTA and non-CTA groups, stratified by gender

	СТ	ΓA	No (	CTA	To	otal	
	(n=2)	232)	(n=1	159)	(n=	391)	р
BMI (n, %)							
Underweight	7	3.1	3	2.0	10	2.6	0.32
Normal BMI	46	20.2	38	25.2	84	22.2	
Overweight	62	27.2	48	31.8	110	29.0	
Obese	113	49.6	62	41.1	175	46.2	
Males							
Underweight	5	4.4	3	2.7	8	3.5	0.64
Normal BMI	25	22.1	28	24.8	53	23.5	
Overweight	32	28.3	38	33.6	70	31.0	
Obese	51	45.1	44	38.9	95	42.0	
Females							
Underweight	2	1.7	0	0.0	2	1.3	0.61
Normal BMI	21	18.3	10	26.3	31	20.3	
Overweight	30	26.1	10	26.3	40	26.1	
Obese	62	53.9	18	47.3	80	47.4	
BMI (mean, SD)	30.9	8.5	29.4	6.5	30.3	7.8	0.07
Males	30.2	9.3	28.9	5.9	29.5	7.8	0.19
Females	31.5	7.7	31.0	7.9	31.4	7.7	0.69

Overall, 73 participants (19.4%) self-reported experiencing hypertension (Table 4.5b). However, it is evident that these rates are potentially much higher than evident in the table as 49.9 per cent of the sample also met the criteria for diastolic hypertension, and 39.1 per cent met the criteria for systolic hypertension. There were no significant differences between the CTA and non-CTA groups.

Table 4.5b: Experience of hypertension for CTA and non-CTA groups, stratified by gender

	CT (n=7	ΓA 232)		CTA 159)		otal 391)	р
Hypertension (n, %)	(11 2	232)	(11	137)	(11	371)	Р
Hypertension (self-reported)	48	21.2	25	16.6	73	19.4	0.26
Males	22	19.8	17	15.3	39	17.6	0.38
Females	26	22.6	8	20.0	34	21.9	0.73
Diastolic hypertension (≥85 mmHg)	112	48.3	83	52.2	195	49.9	0.45
Males	59	51.8	59	51.8	118	51.8	1.00
Females	53	44.9	24	53.3	77	47.2	0.36
Systolic hypertension (≥130 mmHg)	88	37.9	65	40.9	153	39.1	0.56
Males	55	48.3	50	43.9	105	46.1	0.51
Females	33	28.0	15	33.3	48	29.5	0.50

Table 4.5c indicates the proportion of SHIP participants with at-risk levels (low) of HDL-C (low levels of HDL increase the risk of heart disease). The table also highlights the levels of HDL, total cholesterol, triglycerides and glucose as measured by the blood test. A greater proportion of the CTA-negative group than expected were classified as having at-risk levels of HDL-C ( $\chi$ 2=5.71, df=1, p=0.017), and they were also more likely than the CTA group to have lower levels of HDL-C (1.2 mmol/L vs 1.1 mmol/L; t=2.66, df=340, p=0.008). A significantly greater proportion of women without a history of CTA had at-risk levels of HDL-C (46.5% vs. 67.5%;  $\chi$ 2=5.05, df=1, p=0.025), while women in the CTA group were found to have significantly higher levels of total cholesterol (t=2.95, df=142, p=0.004).

Table 4.5c: HDL, total cholesterol, triglycerides and glucose blood results for CTA and non-CTA groups, stratified by gender

	C'	TA	No (	CTA	To	tal	
	(n	=232)	(n=1)	159)	(n=	391)	р
Blood results (n, %)							
HDL risk (n, %)	88	45.6	78	59.1	166	51.1	0.017
Males	41	44.6	51	55.4	92	50.0	0.14
Females	47	46.5	27	67.5	74	52.5	0.025
HDL (mmol/L) (mean, SD)	1.2	0.4	1.1	0.4	1.2	0.4	0.008
Males	1.1	0.4	1.1	0.3	1.1	0.4	0.24
Females	1.3	0.4	1.2	0.4	1.2	0.4	0.10
Total cholesterol (mean, SD)	5.2	1.2	5.0	1.1	5.1	1.2	0.08
Males	5.1	1.3	5.1	1.2	5.1	1.3	0.98
Females	5.3	1.1	4.8	0.9	5.2	1.1	0.004
Triglycerides (mmol/L) (mean, SD)	1.9	1.3	2.2	1.6	2.0	1.4	0.06
Males	2.0	1.4	2.2	1.7	2.1	1.5	0.21
Females	1.8	1.2	2.0	1.5	1.9	1.3	0.34
Glucose (mmol/L) (mean, SD)	5.3	1.3	5.4	1.5	5.3	1.4	0.48
Males	5.4	1.4	5.4	1.5	5.4	1.5	0.81
Females	5.1	1.2	5.4	1.3	5.2	1.2	0.27

Table 4.6 indicates there were no significant group differences identified in the lifetime prevalence of alcohol abuse/dependence, cannabis abuse/dependence, or other substance abuse/dependence.

Table 4.6: Lifetime alcohol, cannabis and other substance abuse/dependence for the CTA and non-CTA groups, stratified by gender

	_	ΓA 232)		CTA 159)		otal 391)	р
Alcohol (n, %)							
Lifetime alcohol	93	40.1	70	44.0	163	41.7	0.44
abuse/dependence							
Male	55	48.3	52	45.6	107	46.9	0.69
Female	38	32.3	18	40.0	56	34.4	0.35
Drug use (n, %)							
Lifetime cannabis	95	41.0	78	49.1	173	44.3	0.11
abuse/dependence	61	50.5		5.4.4	100	540	0.00
Male	61	53.5	62	54.4	123	54.0	0.89
Female	34	28.8	16	35.6	50	30.7	0.40
Lifetime other substance abuse/dependence (n,	75	32.3	48	30.2	123	31.5	0.66
%)							
Male	47	41.2	33	29.0	80	35.1	0.052
Female	28	23.7	15	33.3	43	26.4	0.21

Table 4.7 indicates that 72.5 per cent of the SHIP cohort smoked cigarettes daily (71.1% for the CTA group and 74.5% for the non-CTA group). Participants were smoking 18.3 cigarettes per day (CTA group: 18.3/day vs. the non-CTA group: 18.2/day). There were no differences between the genders.

Table 4.7: Smoking status for CTA and non-CTA groups, stratified by gender

	CT. (n=2.			CTA 159)		otal 391)	р
Lifetime smoking status (n, %)							
Never smoked	35	15.1	20	12.7	55	14.1	0.74
Ex-smoker	32	13.8	20	12.7	52	13.4	
Current smoker	165	71.1	117	74.5	282	72.5	
Males (n, %)							
Never smoked	17	14.9	13	11.6	30	13.3	0.69
Ex-smoker	15	13.2	13	11.6	28	12.4	
Current smoker	82	71.9	86	76.8	168	74.3	
Females (n, %)							
Never smoked	18	15.3	7	15.6	25	15.3	0.98
Ex-smoker	17	14.4	7	15.6	24	14.7	
Current smoker	83	70.3	31	68.9	114	69.9	
Current smoking							
Cigarettes per day (mean±SD)	18.3	12.8	18.2	13.3	18.3	13.0	0.91
Males	20.2	13.7	18.9	13.4	19.5	13.5	0.50
Females	16.6	11.7	16.3	12.9	16.5	12.0	0.93

Table 4.8 depicts both the current and lifetime prevalence of alcohol use. While there were no significant differences overall between the CTA and non-CTA groups, more females who had experienced CTA than expected reported lifetime use of alcohol when compared with females who had not experienced CTA ( $\chi$ 2=5.1, df=1, p=0.024). However, females who had not experienced CTA were more likely to have used alcohol in the year prior to the SHIP interview ( $\chi$ 2=4.8, df=1, p=0.028).

Table 4.8: Lifetime and current alcohol use for CTA and non-CTA groups, stratified by gender

	CTA (n=232)		No CTA (n=159)		Total (n=391)		р
Lifetime use (n, %)	217	93.5	145	91.8	362	92.8	0.51
Male	108	94.7	108	96.5	217	95.6	0.53
Female	109	92.4	36	80.0	145	89.0	0.024
Past year use (n, %)	171	78.8	119	82.1	290	80.1	0.45
Male	90	83.3	86	78.9	176	81.1	0.40
Female	81	74.3	33	91.7	114	78.6	0.028

Table 4.9 indicates high rates of lifetime use of illicit drugs in the South Australian SHIP cohort, with 71.8 per cent of participants having used cannabis at some time in their life. While there were no significant differences overall between the CTA group and non-CTA group in both current and lifetime cannabis use, more males with a history of CTA than expected reported using cannabis in the year prior to the SHIP interview ( $\chi$ 2=4.5, df=1, p=0.033).

Table 4.9: Lifetime and current cannabis use for CTA and non-CTA groups, stratified by gender

	C	ГА	No (	CTA	To	otal	
	(n=232)		(n=159)		(n=391)		p
Lifetime use (n, %)	167	72.0	113	71.5	280	71.8	0.92
Males	92	80.7	89	78.8	181	79.7	0.72
Females	75	63.6	24	53.3	99	60.7	0.23
Past year use (n, %)	92	39.7	53	33.3	145	37.1	0.20
Males	59	51.8	43	37.7	102	44.7	0.033
Females	33	28.0	10	22.2	43	26.4	0.46

The CTA group generally indicated higher rates of reported lifetime physical health conditions (Table 4.10). More of the CTA-positive group experienced higher rates of chronic pain ( $\chi$ 2=18.24, df=1, p=0.001), headaches and migraines ( $\chi$ 2=19.73, df=1, p=001), arthritis ( $\chi$ 2=10.88, df=1, p=0.001) and asthma ( $\chi$ 2=5.52, df=1, p=0.019). Cardiovascular disease and/or stroke were also more common in the CTA-positive group

( $\chi$ 2=9.80, df=1, p=0.002). More males with a history of CTA than expected reported chronic pain ( $\chi$ 2=5.2, df=1, p=0.022), cardiovascular disease/stroke ( $\chi$ 2=7.9, df=1, p=0.005), headaches/migraines ( $\chi$ 2=10.0, df=1, p=0.001), arthritis ( $\chi$ 2=4.7, df=1, p=0.031) and epilepsy ( $\chi$ 2=5.3, df=1, p=0.021). More females with CTA than expected reported chronic pain ( $\chi$ 2=9.8, df=1, p=0.002) and headaches/migraines ( $\chi$ 2=6.2, df=1, p=0.012).

Table 4.10: Self-reported lifetime history of physical conditions for CTA and non-CTA groups, stratified by gender

	C	ГΑ	No	CTA	To	otal	
	(n=	232)	(n=	159)	(n=	391)	p
Lifetime physical							
conditions (n, %)							
Chronic pain	101	43.5	35	22.4	136	35.1	< 0.001
Asthma	81	34.9	37	23.7	118	30.4	0.019
Cardiovascular/stroke	54	23.5	17	10.9	71	18.4	0.002
Severe headaches/migraines	89	38.4	27	17.3	116	29.9	< 0.001
Arthritis	64	27.6	21	13.5	85	21.9	0.001
Diabetes	56	24.5	39	25.2	95	24.7	0.88
Epilepsy	25	10.8	10	6.5	35	9.0	0.15
Cancer	11	4.7	4	2.6	15	3.9	0.28
Males (n, %)							
Chronic pain	41	36.0	25	22.1	66	29.1	0.022
Asthma	33	29.0	24	21.2	57	25.1	0.18
Cardiovascular/stroke	27	23.7	11	9.7	38	16.7	0.005
Severe headaches/migraines	39	34.2	18	15.9	57	25.1	0.001
Arthritis	20	17.5	9	8.0	29	12.8	0.031
Diabetes	26	23.2	24	21.4	50	22.3	0.75
Epilepsy	18	15.8	7	6.2	25	11.0	0.021
Cancer	2	1.8	3	2.7	5	2.2	0.64
Females (n, %)							
Chronic pain	60	50.9	10	23.3	70	43.5	0.002
Asthma	48	40.7	13	30.2	61	37.9	0.23
Cardiovascular/stroke	27	23.3	6	14.0	33	20.8	0.20
Severe headaches/migraines	50	42.4	9	20.9	59	36.7	0.012
Arthritis	44	37.3	12	27.9	56	34.8	0.27
Diabetes	30	25.6	15	34.9	45	28.1	0.25
Epilepsy	7	5.9	3	7.1	10	6.3	0.78
Cancer	9	7.6	1	2.3	10	6.2	0.21

The CTA group also reported higher rates of health service utilisation (Table 4.11). This cohort attended emergency departments on more occasions ( $\chi 2=5.90$ , df=1, p=0.015) and was more likely to have visited their GP in the previous 12 months ( $\chi 2=6.89$ , df=1, p=0.009). Sixty two per cent of participants reported they had visited a GP in the previous

year for a mental health related reason. There was no significant difference between the two groups regarding their use of mental health and other general health services.

Table 4.11: Health service utilisation for CTA and non-CTA groups, stratified by gender

		ΓA	No (			otal	
Service utilisation (past year) (n,	(n=2	232)	(n=	159)	(n=.	391)	р
%)							
Inpatient admission, any	126	54.3	76	47.8	202	51.7	0.21
Mental health	98	42.2	60	37.7	158	40.4	0.37
Physical health	45	19.4	27	17.0	72	18.4	0.55
Involuntary admission	55	23.7	30	18.9	85	21.7	0.25
Community treatment order	31	13.4	32	20.1	63	16.1	0.07
Emergency department attendance	144	62.1	79	49.7	223	57.0	0.015
Outpatient/community clinic contact	210	90.5	141	88.7	351	89.8	0.56
Home visit, any	116	50.0	89	56.0	205	52.4	0.25
Case manager, any	103	44.4	83	52.2	186	47.6	0.13
GP visits, any	220	94.8	139	87.4	359	91.8	0.009
No. of visits (mean±SD)	11.8	14.5	12.6	16.5	12.1	15.4	0.62
Males (n, %)							
Inpatient admission, any	62	54.4	50	43.9	112	49.1	0.11
Mental health Physical health	48	42.1	42	36.8	90	39.5	0.42
Involuntary admission	26	22.8	21	18.4	47	20.6	0.41
Community treatment order	17	14.9	24	21.1	41	18.0	0.23
Emergency department attendance	66	57.9	52	45.6	118	51.8	0.06
Outpatient/community clinic contact	105	92.1	104	91.2	209	91.7	0.81
Home visit, any	54	47.4	61	53,5	115	50.4	0.35
Case manager, any	47	41.2	59	51.8	106	46.5	0.11
GP visits, any	106	93.0	97	85.1	203	89.0	0.06
No. of visits (mean±SD)	11.1	15.6	12.2	16.3	11.6	15.9	0.62
Females (n, %)							
Inpatient admission, any	64	54.2	26	57.8	90	55.2	0.68
Mental health Physical health	50	42.4	18	40.0	68	41.7	0.78
Involuntary admission	29	24.6	9	20.0	38	23.3	0.54
Community treatment order	14	11.9	8	17.8	22	13.5	0.32
Emergency department attendance	78	66.1	27	60.0	105	64.4	0.47
Outpatient/community clinic contact	105	89.0	37	82.2	142	87.1	0.25
Home visit, any	62	52.5	28	62.2	90	55.2	0.27
Case manager, any	56	47.5	24	53.3	80	49.1	0.50
GP visits, any	114	96.6	42	93.3	156	95.7	0.36
No. of visits (mean±SD)	12.5	13.6	13.6	17.3	12.8	14.6	0.67

# 4.3.1.4 Social and Economic Characteristics of the SHIP Sample

Just over a fifth (21.7%) of participants had completed the final year of schooling (Table 4.12). Fewer females with a history of CTA than expected completed Year 12 ( $\chi$ 2=7.9, df=3, p=0.047) and both genders with a history of CTA were significantly younger when they left school (females: t=-2.1, df=161, p=0.04; males: t=-2.4, df=226, p=0.015).

Table 4.12: Level of schooling completed and age left school for CTA and non-CTA groups, stratified by gender

	CT	ΓA	No (	CTA	To	otal	
	(n=2)	232)	(n=1	159)	(n=	391)	p
Level of school completed (n, %)							
Year 9 or below	64	27.7	30	19.1	94	24.2	0.021
Year 10	84	36.4	46	29.3	130	33.5	
Year 11	40	17,3	40	25.5	80	20.6	
Year 12	43	18.6	41	26.1	84	21.7	
Males							
Year 9 or below	29	25.7	23	20.4	52	23.0	0.164
Year 10	47	41.6	37	32.7	84	37.2	
Year 11	15	13.2	25	22.1	40	17.7	
Year 12	22	19.5	28	24.8	50	22.1	
Females							
Year 9 or below	35	29.7	7	15.9	42	25.9	0.047
Year 10	37	31.4	9	20.5	46	28.4	
Year 11	25	21.2	15	34.1	40	24.7	
Year 12	21	17.8	13	29.6	34	21.0	
Age left school (mean±SD)	15.8	1.3	16.3	1.2	16.0	1.3	0.001
Males	15.8	1.3	16.3	1.6	16.0	1.1	0.015
Females	15.9	1.3	16.3	1.1	16.0	1.2	0.04

As Table 4.13 demonstrates, in the week prior to interview, 16.1 per cent of the SHIP cohort were in paid employment. This figure rose to 23.5 per cent for any employment in the previous 12 months. There were no differences between the CTA positive and negative groups or by gender.

Table 4.13: Employment status in the week and year prior to interview for CTA and non-CTA groups, stratified by gender

	_	TA 232)		CTA =159)		otal =391)	р
Employment type (n, %)	•		•		•	•	•
Paid employment (past week)	38	16.4	25	15.7	63	16.1	0.82
Paid employment (past year)	54	23.3	38	23.9	92	23.5	0.89
Males							
Paid employment (past week)	18	15.8	18	15.8	36	15.8	1.00
Paid employment (past year)	27	23.7	27	23.7	42	23.7	1.00
Females							
Paid employment (past week)	20	17.0	7	15.6	27	16.6	0.83
Paid employment (past year)	27	22.9	11	24.4	38	23.3	0.83

Table 4.14 depicts the reasons why SHIP participants who were not currently employed were not looking for work. Among those not actively pursuing employment (n=245), the most frequently given reasons for not looking for work were: 'own ill health or physical disability' (82.2%); 'not wanting to work' (51.4%); and 'welfare payments/pension may be affected' (48.2%).

Overall, participants with a CTA history reported they were less likely to seek employment due to physical health/disability ( $\chi$ 2=5.62, df=1, p=0.018), because they believed their welfare/disability pension income was likely to be affected ( $\chi$ 2=14.4, df=1, p<0.001), and/or because they felt they lacked adequate schooling or skills ( $\chi$ 2=7.6, df=1, p=0.006).

More males with a history of CTA than expected were not looking for work due to their physical health/disability ( $\chi$ 2=5.5, df=1, p=0.019) or due to their low level of schooling and/or skills capacity ( $\chi$ 2=4.7, df=1, p=0.030). More females from the CTA group than expected were not looking for work due to its effect on their welfare/pension income ( $\chi$ 2=8.1, df=1, p=0.005).

Table 4.14: Reasons for not looking for work among those not in the workforce (n=245)

Reasons (n, %) Do not want to work 70 Physical health/disability 12	(n=145)		(n=100)	))	(		
Do not want to work 76	5 5			' /	(n=245	))	p
	5						
Physical health/disability 12		52.4	50	50	126	51.4	0.71
		37.0	76	75.3	203	82.2	0.018
Welfare payments/pension 83	5 5	58.2	34	33.7	119	48.2	< 0.001
may be affected							
Childcare 14		9.6	9	8.9	23	9.3	0.86
Others' ill health		7.5	6	5.9	17	6.9	0.63
Other family 2	1 1	4.4	7	6.9	28	11.3	0.07
considerations							
Employers think too 20	) 1	3.7	8	7.9	28	11.3	0.16
young/old							
No suitable jobs	5 1	0.3	7	6.9	22	8.9	0.36
Lacks schooling/skills 5	1 3	34.9	19	18.8	70	28.3	0.006
_							
Males							
Do not want to work 33	3 4	17.1	40	55.6	73	51.4	0.32
Physical health/disability 64	4 9	0.1	55	75.3	119	82.6	0.019
Welfare payments/pension 40	) 5	6.3	26	35.6	66	45.8	0.013
may be affected							
Childcare 3		4.2	3	4.1	6	4.2	0.97
Others' ill health 6		8.5	3	4.1	9	6.3	0.28
Other family 7		9.9	4	5.5	11	7.6	0.32
considerations							
Employers think too	1 1	5.5	5	6.9	16	11.1	0.10
young/old			· ·	0.5	10		0.10
No suitable jobs 8	. 1	1.3	6	8.2	14	9.7	0.54
Lacks schooling/skills 25		35.2	14	19.2	39	27.1	0.03
Eucks senooning/skins 2.	, ,	75.2	1.	17.2	37	27.1	0.03
Females							
Do not want to work 4.	3 5	57.3	10	35.7	53	51.5	0.051
Physical health/disability 63		34.0	21	75.0	84	81.6	0.30
Welfare payments/pension 4:		50.0	8	28.6	53	51.5	0.005
may be affected		0.0	O	20.0	33	31.3	0.005
Childcare 1	1 1	4.7	6	21.4	17	16.5	0.41
Others' ill health 5		6.7	3	10.7	8	7.8	0.41
Other family		8.7	3	10.7	17	16.5	0.30
considerations	т I	0.7	J	10./	1 /	10.5	0.55
Employers think too 9	, 1	2.0	3	10.7	12	11.7	0.86
young/old		2.0	5	10./	1 4	11./	0.00
No suitable jobs 7	,	9.3	1	3.6	8	7.8	0.33
Lacks schooling/skills 20		9.3 34.7	5	3.0 17.9	31	30.1	0.33
Lacks schooling/skills 20	<i>)</i> 3	94./	S	1 / .9	31	30.1	0.10

The majority of the sample had an income of AU\$500-799 per fortnight (Table 4.15).

There were no significant differences between the CTA and non-CTA groups.

Table 4.15: Income per fortnight for CTA and non-CTA groups, stratified by gender

	C	ГА	No (	CTA	To	otal	
	(n=1)	232)	(n=	159)	(n=	391)	p
Income (per fortnight) (n,							
%)							
Less than \$300	12	5.2	13	8.2	25	6.4	0.64
\$300-\$499	36	15.5	21	13.2	57	14.6	
\$500-\$799	147	63.4	101	63.5	248	63.4	
\$800-\$1000	22	9.5	17	10.7	39	10.0	
More than \$1000	15	6.5	7	4.4	22	5.6	
Males							
Less than \$300	4	3.5	10	8.8	14	6.1	0.34
\$300-\$499	19	16.7	16	14.0	35	15.3	
\$500-\$799	75	65.8	77	67.5	152	66.7	
\$800-\$1000	9	7.9	8	7.0	17	7.5	
More than \$1000	7	6.1	3	2.6	10	4.4	
Females							
Less than \$300	8	6.8	3	6.7	11	6.8	0.60
\$300-\$499	17	14.4	5	11.1	22	13.5	
\$500-\$799	72	61.0	24	53.3	96	58.9	
\$800-\$1000	13	11.0	9	20.0	22	13.5	
More than \$1000	8	6.8	4	8.9	12	7.4	

Seventy-one per cent of participants reported that they had been functioning normally in their work and/or study roles prior to the onset of their psychosis (Table 4.16), and 94.1 per cent reported deterioration in their level of functioning after their illness onset. 24.6 per cent of the total sample reported severe dysfunction in self-care in the four weeks prior to interview. Little difference is evident between the CTA and non-CTA groups regarding their functioning.

Less of the CTA group than expected were satisfied with their current levels of independence ( $\chi$ 2=5.0, df=1, p=0.025); further investigation revealed that more males with a history of CTA were particularly less satisfied with their independence ( $\chi$ 2=5.2, df=1, p=0.022) than the non-CTA men.

Table 4.16: Day-to-day functioning for CTA and non-CTA groups, stratified by gender

	_	ГΑ		CTA		otal	
	(n=2	232)	(n=	159)	(n=	391)	р
Functioning and quality of life (n, %)							
Good pre-morbid work adjustment	171	73.7	108	67.9	279	71.4	0.21
Males	75	65.8	72	63.2	147	64.5	0.68
Females	96	81.4	36	80.0	132	81.0	0.84
Deterioration of pre- morbid level of functioning	219	94.4	149	93.7	368	94.1	0.78
Males	105	92.1	109	95.6	214	93.9	0.27
Females	114	96.6	40	88.9	154	94.5	0.054
Severe dysfunction in self- care	55	23.7	41	25.8	96	24.6	0.64
Males	27	23.7	34	29.8	61	26.8	0.30
Females	28	23.7	7	15.6	35	21.5	0.26
Satisfied with independence <sup>16</sup>	162	70.1	126	80.25	288	74.23	0.025
Males	78	69.0	92	82.1	170	75.6	0.022
Females	84	71.2	34	75.6	118	72.4	0.58
Satisfied with life <sup>17</sup>	101	44.1	83	52.2	184	47.4	0.12
Males	46	41.4	59	51.8	105	46.7	0.12
Females	55	46.6	24	53.3	79	48.5	0.44

Table 4.17 depicts quality of life in the SHIP cohort, as measured by the Assessment of Quality of Life (AQOL). The CTA-positive group reported significantly worse psychological wellbeing (t=-3.95, df=382, p=<0.001) and overall quality of life (t=-2.25, df=382, p=0.025) than the non-CTA group. Males with a history of CTA reported significantly worse psychological wellbeing (t=-3.2, df=226, p=0.002).

Very or somewhat satisfied.Delighted, very pleased or mostly satisfied.

Table 4.17: Means and standard deviations for the Assessment of Quality of Life (AQOL) Questionnaire for CTA and non-CTA groups, stratified by gender

	СТ	'Α	No C	CTA	То	tal	
	(n=2	(32)	(n=1	59)	(n=3)	391)	р
AQOL (Utility)							
Independent living	0.82	0.2	0.86	0.2	0.84	0.2	0.07
Social relationships	0.66	0.3	0.68	0.3	0.67	0.3	0.50
Physical senses	0.95	0.1	0.94	0.1	0.95	0.1	0.46
Psychological wellbeing	0.82	0.2	0.89	0.1	0.85	0.2	< 0.001
Overall utility score	0.48	0.3	0.54	0.3	0.50	0.3	0.025
Males							
Independent living	0.85	0.2	0.86	0.2	0.85	0.2	0.58
Social relationships	0.62	0.3	0.65	0.3	0.64	0.3	0.51
Physical senses	0.96	0.1	0.95	0.1	0.95	0.1	0.34
Psychological wellbeing	0.83	0.2	0.90	0.1	0.87	0.2	0.002
Overall utility score	0.47	0.3	0.54	0.3	0.50	0.3	0.08
Females							
Independent living	0.79	0.2	0.85	0.2	0.81	0.2	0.14
Social relationships	0.69	0.3	0.75	0.3	0.71	0.3	0.25
Physical senses	0.95	0.1	0.94	0.1	0.95	0.1	0.73
Psychological wellbeing	0.81	0.2	0.86	0.2	0.82	0.2	0.09
Overall utility score	0.48	0.3	0.56	0.3	0.50	0.3	0.13

Twenty-eight per cent of participants reported poor social functioning prior to the onset of their psychosis (Table 4.18a), and 47.6 per cent reported severe social dysfunction in the 12 months prior to the SHIP interview. There were no significant differences between the CTA and non-CTA groups.

Table 4.18a: Social functioning in the 12 months prior to interview, for CTA and non-CTA groups, stratified by gender

	CT (n=2		No ( (n=1			otal 391)	р
Global social functioning (n, %)	(11 2		(11 )	,	(11	371)	Р
Poor pre-morbid social adjustment	71	30.6	42	26.4	113	28.9	0.37
Males	38	33.3	32	28.1	70	30.7	0.39
Females	33	28.0	10	22.2	43	26.4	0.46
Social dysfunction/deficit	113	48.7	73	45.9	186	47.6	0.59
Males	54	47.4	58	50.9	112	49.1	0.60
Females	59	50.0	15	33.3	74	45.4	0.06
Personal social & performance scale	55.5	14.4	53.3	14.1	54.6	14.3	0.15
(mean±SD)							
Males	53.8	15.1	51.8	14.1	52.8	14.6	0.29
Females	57.1	13.6	57.4	13.5	57.1	13.5	0.90

Most respondents (82.3%) reported they often had contact with family members (Table 4.18b). Nearly three quarters of participants (70.5%) reported having 'a few friends'. However, 82.2 per cent of participants indicated experiencing loneliness, and over half the sample felt a need for more friends (50.7%). There were no differences between the CTA and non-CTA groups.

Table 4.18b: Social contact in the 12 months prior to interview, for CTA and non-CTA groups, stratified by gender

	C7	ΓΑ		CTA	To	otal	
	(n=2	232)	(n=	159)	(n=:	391)	р
Family and friends							
Freq. of face-to-face							
contact with family			_				
- None	12	5.2	7	4.4	19	4.9	0.94
- Seldom	30	12.9	20	12.7	50	12.8	
- Often	190	81.9	131	82.9	131	82.3	
No. of friends							
- None	28	12.1	19	12.0	47	12.1	0.94
- Some	164	71.0	111	69.8	275	70.5	
- Many	39	16.9	29	18.2	68	17.4	
Perceived need for friends							
- Does not need	23	10.1	15	9.6	38	9.9	0.44
- Needs/wants more	121	53.1	74	47.1	195	50.7	
- Has enough	84	36.8	68	43.3	152	39.5	
Perceived loneliness							
Yes	188	85.1	121	78.1	309	82.2	0.08
Never had confiding	39	16.9	29	18.6	68	17.6	0.67
relationship							
Males							
Freq. of face-to-face							
contact with family							
- None	9	7.9	6	5.3	15	6.6	0.72
- Seldom	17	14.9	17	14.9	34	14.9	
- Often	88	77.2	91	79.8	179	78.5	
No. of friends							
- None	15	13.3	16	14.0	31	13.7	0.97
- Some	78	69.0	77	67.5	155	68.3	
- Many	20	17.7	21	18.4	41	18.1	
Perceived need for friends							
- Does not need	11	9.8	11	9.8	22	9.8	0.70
- Needs/wants more	61	54.5	55	49.1	55	51.8	
- Has enough	40	35.7	46	41.1	46	41.1	
Perceived loneliness							
Yes	91	85.9	84	75.7	175	80.7	0.06
Never had confiding	29	25.4	24	21.4	53	23.5	0.48
relationship	2)	23.1	2.	21.1	33	23.3	0.10
Females							
Freq. of face-to-face							
contact with family							
- None	3	2.5	1	2.3	4	2.5	0.72
- Seldom	13	11.0	3	6.8	16	9.9	0.72
- Often	102	86.4	40	90.9	142	9.9 87.7	
No. of friends	102	00.4	40	70.7	144	01.1	
- None	13	11.0	3	6.7	16	9.8	0.70
- None - Some	13 86		3 34				0.70
		72.9		75.6	120	73.6	
- Many Perceived need for friends	19	16.1	8	17.8	27	16.6	
	10	10.2	4	0.0	17	0.0	0.45
- Does not need	12	10.3	4	8.9	16	9.9	0.45
- Needs/wants more	60	51.7	19	42.2	79	49.1	
- Has enough	44	37.9	22	48.9	66	41.0	
Perceived loneliness	0 =	0	. –	0	46.	0.4.5	
Yes	97	84.4	37	84.1	134	84.3	0.97
Never had confiding relationship	10	8.6	5	11.4	15	9.3	0.58

More of the CTA-positive group had no-one to rely on when experiencing serious personal problems ( $\chi$ 2=8.1, df=1, p=0.018) including less reliance on family for support (Table 4.18c). Additionally, more males with a history of CTA than expected reported that they had no-one to rely on when in need of emotional or social support ( $\chi$ 2=8.6, df=1, p=0.014).

Table 4.18c: Supportive relationships in the 12 months prior to interview, for CTA and non-CTA groups, stratified by gender

		ΓA 232)		CTA 159)		otal 391)	р
Availability of supportive	•	- /	`			,	r
relationships (n, %)							
Someone to rely on							
- No-one	37	16.0	12	7.6	49	12.6	0.018
- Family	144	62.1	117	74.5	261	67.1	
- Friends	51	22.0	28	17.8	79	20.3	
Males							
Someone to rely on							
- No-one	28	24.6	11	9.8	39	17.3	0.014
- Family	68	59.7	80	71.4	148	65.5	
- Friends	18	15.8	21	18.8	21	17.3	
Females							
Someone to rely on							
- No-one	9	7.6	1	2.2	10	6.1	0.08
- Family	76	64.4	37	82.2	113	69.3	
- Friends	33	28.0	7	15.6	40	24.5	

Thirty-six per cent of the SHIP participant group experienced some form of stigma, with an additional 56.3 per cent of participants fearful of experiencing stigma (Table 4.19). More of the CTA-positive group reported experiencing stigma and/or discrimination in the previous 12 months ( $\chi$ 2=9.9, df=1,p=0.002), and separate analyses by gender indicated that more of the male CTA group than expected experienced stigma due to mental illness ( $\chi$ 2=4.1, df=1, p=0.043).

Table 4.19: Social stigmatisation in the 12 months prior to interview, for CTA and non-CTA groups, stratified by gender

CTA (n=232)		No CTA (n=159)		Total (n=391)			
						р	
100	43.3	44	27.7	144	36.9	0.002	
53	54.1	27	61.4	80	56.3	0.42	
50	50.5	26	60.5	76	53.5	0.27	
44	38.9	30	26.3	74	32.6	0.043	
19	44.2	15	50.00	34	46.9	0.62	
17	39.5	14	48.3	31	43.1	0.46	
56	47.5	14	31.1	70	42.9	0.06	
34	61.8	12	85.7	46	66.7	0.09	
33	58.9	12	85.7	45	64.3	0.06	
	100 53 50 44 19 17	(n=232)  100	(n=232) (n=  100	(n=232) (n=159)  100 43.3 44 27.7 53 54.1 27 61.4 50 50.5 26 60.5  44 38.9 30 26.3 19 44.2 15 50.00 17 39.5 14 48.3  56 47.5 14 31.1 34 61.8 12 85.7	(n=232) (n=159) (n=  100 43.3 44 27.7 144  53 54.1 27 61.4 80  50 50.5 26 60.5 76  44 38.9 30 26.3 74  19 44.2 15 50.00 34  17 39.5 14 48.3 31  56 47.5 14 31.1 70  34 61.8 12 85.7 46	(n=232)         (n=159)         (n=391)           100         43.3         44         27.7         144         36.9           53         54.1         27         61.4         80         56.3           50         50.5         26         60.5         76         53.5           44         38.9         30         26.3         74         32.6           19         44.2         15         50.00         34         46.9           17         39.5         14         48.3         31         43.1           56         47.5         14         31.1         70         42.9           34         61.8         12         85.7         46         66.7	

Table 4.20 indicates that there are no significant differences between the CTA and non-CTA groups regarding criminal offending. However, the experience of victimisation and violence was prevalent, with 23.5 per cent of participants experiencing violence and intimidation in the 12 months prior to interview. More of the CTA-positive group reported having been the victim of violence in the year prior to the SHIP interview ( $\chi$ 2=7.7, df=1, p=0.006). Additionally, more males with CTA than expected reported the experience of violence in the past 12 months ( $\chi$ 2=7.1, df=1, p=0.008).

Table 4.20: Victimisation and offending, in the 12 months prior to interview, for CTA and non-CTA groups, stratified by gender

	CTA (n=232)		No CTA (n=159)		Total (n=391)		р	
Victimisation and offending (n, %)								
Victim of violence (inc. threatened violence)	66	28.5	26	16.4	92	23.5	0.006	
Male	35	30.7	18	15.8	53	23.3	0.008	
Female	31	26.3	8	17.8	39	23.9	0.26	
Arrested or charged with an offence	25	10.8	14	8.8	39	10.0	0.52	
Male	14	14.9	12	10.5	29	12.7	0.32	
Female	8	6.8	2	4.4	10	6.1	0.58	

I used multivariate logistic regression models to examine whether participants who report CTA have different demographic, physical health and psychosocial profiles compared to participants who did not report CTA. Table 4.21 displays the results of the final multiple logistic regression model for males and females, adjusted for age at the time of the SHIP interview. Despite the fact that numerous physical, psychological and social/functioning variables had been significant at the univariate level, many of these variables were not significant in the multivariate models. Males who had experienced CTA were less likely to feel as though they had family that they could rely on. They were more likely to report a lifetime history of cardiovascular disease and/or stroke, migraines and anhedonia. They were also significantly more likely to report experiencing victimisation in the past year. Females who had experienced CTA were more likely to have high cholesterol and report a lifetime history of chronic pain. Both age and lifetime alcohol use approached significance. None of the psychological symptoms were significant for the females at the multivariate level.

Table 4.21: Relationship between CTA and demographics, psychological and physical health profiles in people with psychosis, stratified by gender

	N	Males	Females				
	OR	95% CI	р	OR	95% CI	p	
Age at interview	0.98	0.95-1.01	0.44	1.04	1.00-1.09	0.074	
Lifetime physical and psychological							
symptoms							
Cardiovascular disease/stroke	2.64	1.15-6.05	0.022				
Migraines	2.30	1.15-4.61	0.019				
Anhedonia	2.19	1.11-4.32	0.024				
Cholesterol				1.71	1.02 - 2.86	0.041	
Chronic pain				3.53	1.17-10.67	0.025	
Lifetime alcohol use				3.90	0.86 - 7.64	0.077	
Someone to rely on							
None	Reference category						
Family	0.41	0.18 - 0.96	0.039				
Friends	0.37	0.13 - 1.01	0.053				
Victimisation	2.48	1.23-4.99	0.011				

4.4 Study One: Discussion

4.4.1 Overview

As I have discussed, SHIP participants reside in the northern region of Adelaide, South

Australia. Social and economic ABS demographic data from Tables 4.1a, 4.1b and 4.1c

highlight the high prevalence of poverty and social disadvantage in the South Australian

SHIP sample. This is compared with both the national and South Australian non-psychosis

populations. This finding replicates a large body of literature that has established clear

links between poverty and the high prevalence of mental illnesses, including psychosis,

major depression and other subtypes of psychopathology (Boardman, Hodgson et al.

1997).

Few differences in illness symptomology were evident between the CTA and non-CTA

groups in the South Australian SHIP cohort. Both the CTA and non-CTA groups

experience comparable levels of physical illness. However there were a small number of

differences that remained in the multivariate analysis, particularly with the self-reporting

of a history of cardiovascular disease/stroke and migraines in males as well as chronic pain

in females.

Education and vocational data indicates higher functioning participation levels in the non-

CTA group, specifically for level of school completed and the age of leaving school.

However this did not apply for participation in competitive full-time employment (see

Tables 4.12 and 4.13). Analysis of social functioning indicates similar outcomes between

the CTA and non-CTA groups, with contact with family and the number of friendships

indicating little or no difference.

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# 4.4.2 Prevalence and Type of CTA

The prevalence of CTA in the overall SHIP cohort is high. The rate of self-declared CTA amongst the SHIP cohort is comparatively higher than in non-psychosis populations (10-20% for the general population (Glover, 2006). Fifty-nine per cent of participants indicated a history of CTA during the SHIP interview. This percentage reflects the findings of a recent Norwegian study of 305 patients with non-affective and affective psychosis, which indicted that a significant proportion (82%) of patients had experienced abuse in childhood (Larsson, Andreassen et al. 2013).

Sixty-nine participants from the CTA cohort (29%) reported a history of CSA. Forty-nine participants (21%) reported a history of physical abuse, while 7 per cent (n=18) reported that they had experienced some form of bullying during their childhood. The type of CTA experienced differed between the genders. More females reported the experience of CSA while males reported greater levels of bullying. These gender differences are also characteristic of the types of CTA experiences reported in the general population (Briere & Elliott, 2003).

The lived experience(s) of both psychosis and CTA has created multifaceted social and economic challenges for many of the South Australian SHIP cohort. As I have highlighted, Study One demonstrates that the cohort predominantly resides in socially and economically disadvantaged circumstances. A high proportion of the cohort experience difficulties with many of the domains of life, including health, economic, social and living circumstances.

#### 4.4.3 Socio-demographic and Functional Differences

Univariate analyses revealed a number of differences between participants who had experienced CTA and those who had not. The CTA group were more likely to be married or in a de facto relationship. They were also more likely to be divorced, separated or widowed. More broadly, CTA has also been associated with poor marital outcomes in both the community (Finkelhor, Hotaling et al. 1989) and clinical settings (Nelson & Wampler, 2000). Given the higher divorce and marriage rates in this South Australian SHIP sample, it is possible that individuals with CTA were more likely to enter into more relationships that were transitory in nature.

The CTA group was more likely to have had children. The majority of parents with a CTA history lived with their dependent children and were found to parent without obvious signs of dysfunction in the past year. However, 20 per cent of parents who had experienced CTA also reported significant to severe difficulties fulfilling their caring roles. It could be considered that both psychosis and CTA present numerous challenges to a person's capacity to provide sufficient levels of parenting and to fulfil their role as primary caregiver. Additionally, the difficulties managing complex personal responsibilities and life stressors, such as having children, can exacerbate relapses in psychosis (Myin-Germeys, Delespaul et al. 2005). Providing the treatment and care that supports people with psychosis and CTA to manage these challenges requires an integrated mental health system with linked pathways that connect individuals to education and employment opportunities as well as to other social networks. These include schools, community agencies and networks that can provide parenting and family support.

Notably, the CTA group was less likely to be accessing a disability pension compared to the non-CTA group. However, both groups reported that their primary source of income was a pension of some kind (92% for the CTA group compared with 93% for the non-CTA

group). Only 23.5 per cent of the entire SHIP sample was in paid employment in the previous 12 months, and in the week prior to the SHIP interviews 21.5 per cent were in paid employment. By comparison, 72.4 per cent of the general population aged 15 to 64 were employed in July 2010 (Glover, 2006). Therefore it is likely that the participants who had experienced CTA accessed income support such as unemployment benefits or family allowances other than the disability pension.

Participants who had experienced CTA were more likely to have left school at an earlier age and were therefore unlikely to have finished Year 11 or 12. The relationship between a psychiatric disorder, CTA and non-completion of high school has previously been investigated in primarily unrepresentative samples (Broberg, Dyregrov et al. 2005, Fortin, Marcotte et al. 2006). Based on a large population study of 20,000 people, Porsche, Fortuna et al. (2011) identified that CTA increased the likelihood of non-school completion by 65 per cent. Additionally, the relationship between CTA and leaving school early may also be mediated by a psychiatric illness. It should also be noted that, in the context of this sample, school completion rates were poor overall. Less than one-quarter (21.7%) of the entire South Australian SHIP sample completed the final year of schooling, and just under one-half (43.7%) had a post-school qualification (trade certificate or higher). Comparative figures for the general population were 53.0 per cent and 59.4 per cent respectively (Slade, 2011).

Maintaining positive social and emotional relationships proved to be difficult for many participants. For example, 47.6 per cent reported dysfunction in socialising. 17.6 per cent had never experienced a confiding relationship and 12.1 per cent had never had friends. Although most participants (87.4%) reported that they had someone to rely on in times of serious need, those who had experienced CTA (specifically males) were more likely to

report having no-one they could rely on. Numerous studies have found that patients with psychotic disorders and a history of trauma exhibit more social dysfunction compared with psychotic patients without exposure to trauma and/or adversity (Rosenberg, Lu et al. 2007, Davidson, Shannon et al. 2009, Boyette, van Dam et al. 2014).

Additionally, 36.9 per cent of the SHIP participant group experienced some form of stigma; while 56.3 per cent reported that the fear of stigma had stopped them doing things that they wanted to do. Males in the CTA group were significantly more likely to have experienced stigma in the 12 months prior to the SHIP interview. This might be anticipated given the combination of psychotic disorders and certain types of CTA are associated with stigma (Link, Struening et al. 1997). Additionally, the experience of victimisation and violence was also prevalent, with 23.5 per cent of participants experiencing violence and intimidation in the 12 months prior to the SHIP interview. Males with a CTA history were also twice as likely to have experienced violence in the 12 months prior to the SHIP interview than males with no CTA history. This finding has also been replicated in a study by Desai et al. (2002), who identified that the experience(s) of CTA can increase men's risk of experiencing victimisation in adulthood.

Overall the socioeconomic functioning of the South Australian SHIP sample was poor with very few differences between the CTA and non-CTA groups on any of the measures of functioning, both pre-morbid and current. Seventy-one per cent of participants in the overall sample had been functioning normally in their work or social roles prior to the onset of their illness. Following illness onset, 94.1 per cent reported deterioration in their overall level of functioning. There were also few differences in quality of life when the CTA group was compared with the non-CTA group. Notably, both psychological wellbeing, particularly in males and overall quality life, were worse in those who had

experienced CTA compared to those who had not experienced CTA. This is congruent with the findings of Boyette and colleagues (2014), who also found that patients with psychotic disorders with higher levels of CTA experiences generally report lower subjective quality of life.

# 4.4 Physical and Psychological Symptoms

Findings from numerous general population studies have suggested that CTA is associated with increased levels of physical health problems among adults (Wegman & Stetler 2009, Norman, Byambaa et al. 2012). More recently, Widom et al. (2012) found evidence that child abuse and neglect affected adult health status, including increased risk for diabetes, lung disease, malnutrition and vision problems. Not surprisingly, there were significant differences between the CTA group and non-CTA group on a number of different lifetime physical conditions in this SHIP sample. The CTA group indicated they were more likely to have experienced chronic pain, asthma, cardiovascular disease or stroke, migraines and arthritis. There were also some gender differences in the experiences of these disorders: males who had experienced CTA were more likely to report chronic pain, cardiovascular disease or stroke, migraines, arthritis and epilepsy. Females who had experienced CTA were more likely to report chronic pain and migraines compared to those who had not experienced CTA. The CTA group was also less likely to have at-risk levels of HDL-C, particularly the females. Similarly, the actual HDL-C measurements for females in the CTA group indicated higher levels than the female non-CTA group. There was no difference in the levels of LDL between the CTA and non-CTA groups. This is despite females in the CTA group indicating slightly higher LDL levels. However, overall the total cholesterol in CTA females is significantly higher. A possible explanation for the inconsistency in these results could be related to the general level of stress experienced by the entire SHIP population and its effect on lipid metabolism. For example, psychological stress has been demonstrated to cause an increase in sympathetic nervous system response (Douglas 1993, Heim, Newport et al. 2000). Additionally, hormones, such as catecholamines, are usually released as a response to stress to provide fuel, increasing the levels of fatty acids circulating in a person's system (Kubzansky, Koenen et al. 2007). Given the constant exposure to environmental stress resulting from lower socioeconomic status and the accompanying lifestyle factors that the SHIP population experience, this could result in long-term metabolic disorder in the form of dyslipidemia for the entire sample, not just the group who had experienced CTA.

CTA has been linked to numerous psychological symptoms in the general population (Dias, Sales et al. 2014). Relationships have been found between emotional abuse, anxiety and depression (Spertus, Yehuda et al. 2003, Irving & Ferraro 2006). Neglect has been associated with anxiety, depression, somatisation and paranoia (Gauthier, Stollak et al. 1996), while sexual abuse has been associated with anxiety and depression (Briere & Runtz, 1990). In this sample, the CTA group were more likely to report a lifetime history of depressive symptoms, anhedonia, poor concentration, elevated mood and lack of insight. The CTA group was also more likely to report that they were currently experiencing subjective thought disorder, either depressed or elevated mood, and poor concentration. The CTA group clinically also presented in a more complex manner than the non-CTA group. This presents numerous challenges for mental health services in regard to consumers' self-management of complex psychological symptomatology. Ensuring that consumers have the most effective medication that can alleviate acute symptoms is imperative to illness recovery. Equally important is their understanding of the ongoing physical and psychological complexities of their mental illness. This comes from consumers' active involvement in the ongoing planning of their pathways to sustainable recovery.

While there were no differences between participants who experienced CTA and those who had not, over two thirds of the SHIP participant cohort smoked cigarettes daily (72.5%). Participants smoked an average of 18.3 cigarettes per day. This exceeds the rates of smoking in the general population: 20.4 per cent for males, 16.4 per cent for females (ABS 2012). The rate of lifetime cannabis use was also high in the South Australian SHIP cohort, with 71.8 per cent of participants having used cannabis at some time in their life. This compares with 34.8 per cent for the general population (Australian Drug Foundation, 2014). At-risk alcohol use was high in the SHIP sample, with 41.7 per cent of participants consuming at-risk levels of alcohol. This compares with 18.2 per cent for the general population (Australian Drug Foundation, 2014). While these smoking and cannabis usage rates are consistent with other studies in psychosis populations (Kelly & McCreadie, 1999), these results point to a range of health and economic factors that represent challenges for individuals and health services alike.

#### 4.5 Service Utilisation

SHIP participants' health service utilisation in the year prior to being interviewed was high. They also relied heavily on the public system for mental health services. Forty per cent of the sample reported having a mental health related inpatient admission in the year previous to being interviewed, while 21 per cent reported at least one involuntary inpatient admission. However, despite 89 per cent usage of outpatient or community clinic services, only 47 per cent reported having a mental health case manager from the public health services. GPs had the majority of contact with this population, with 62 per cent of participants reporting they had visited a GP in the previous year for mental health related reasons. Participants who had experienced CTA were also more likely to have attended the emergency department or to have attended the GP in the past year. This confirms literature in the field that suggests that CTA is linked with more frequent visits to the GP, especially for mental health related reasons (Glaser, Van Os et al. 2006). CTA is also generally

recognised as an important contributor to somatisation, resulting in frequent health problems and the higher consumption of health services (Schilte, 2001). Thus, Study One confirms the link between CTA and the comparatively high number of GP visits in psychosis/CTA populations, highlighting the complex medical and social needs of the cohort.

#### 4.6 Multivariate Models

The univariate analyses of physical and psychological symptoms, and socio-demographic data indicate differences between CTA and non-CTA participants. However, most of these findings were not significant in the age-adjusted multiple logistic regression models. This univariate analysis indicated that males who had experienced CTA were more likely to report a lifetime history of cardiovascular disease or stroke, and migraines. They were also significantly more likely to report a lifetime history of anhedonia. Males were also more likely to be a victim of violence in the past year and less likely to feel as though they could rely on family members for support.

Conversely, the only variables that proved to be significant in the multivariate analysis for the females were two variables related to physical health. In females, for each unit (mmol/L) increase in total cholesterol, the odds of having the experience of CTA increase by 70 per cent. Also females who had experienced CTA were significantly more likely to report a lifetime chronic pain. Despite discussion in the literature to the contrary (Bendall, Jackson et al. 2010, Dvir, Denietolis et al. 2013), the Study One analysis does not provide sufficient evidence of a relationship between CTA and psychosis. There were no significant differences between the group of psychological symptoms specific to psychosis (i.e. hallucinations, delusions, subjective thought disorder) or the course and duration of psychosis. Additionally, the psychological symptoms that were more likely to be related to

CTA in the general population (e.g. anhedonia) were also significant in this psychosis population.

Few variables contributed to either model. This may be due to the ill-defined nature of how CTA was identified in the SHIP study. The definition of CTA in the SHIP study consisted of numerous types of CTA. Consequently, the models derived from the SHIP data that I am using in this research may also be weaker given that SHIP participants were only asked about the broad experience(s) of CTA. Consequently, if CTA was a more defined or focused question in the SHIP research interview schedule, the models as defined in this PhD research might lead to a more comprehensive framework in which to make conclusions and recommendations from the SHIP data.

Additionally, there have been conflicting reports in the literature about the nature of the dose-response relationship between psychological and physical health predictors and the actual number or intensity of CTA experiences (Edwards, Holden et al. 2003, Raposa, Hammen et al. 2014). It is likely there are groups in this population that experienced a more severe form of CTA over a long time frame, and these participants are being included with people who may have only experienced a single, less severe CTA event(s).

Finally, the use of illicit drugs by a significant portion of the SHIP cohort may negate any potential links between CTA and poor health and psychosocial outcomes. Literature in the field suggests that the association between the experience(s) of CTA and poor health and psychosocial outcomes in the general population is common (Dube, Felitti et al. 2003, Anda, Felitti et al. 2006). However, for psychosis/CTA populations, the literature about the influence of CTA and drug use in psychosis is less clear.

#### 4.7 Study One Findings

Several findings have emerged from Study One. It is evident from the quantitative analysis of the South Australian SHIP data that individual participants present with a complex health and social profile. Overall, the entire South Australian SHIP cohort presented with numerous physical health problems. These included elevated levels of cholesterol, BMI, hypertension, diabetes and numerous other physical illnesses. However, although there were differences in some psychological, physical health and social outcomes between the CTA and non-CTA groups, overall functioning in these domains did not appear to be adversely affected by the experience(s) of CTA. A significant portion of non-psychosis trauma in the literature links CTA to deficits in areas such as psychological and social functioning (Mulvihill, 2005) as well as health functioning (Norman, Means-Christensen, et al. 2006). Nonetheless, the SHIP sample unexpectedly did not replicate this association, either at a univariate or multivariate level of analysis.

Despite the high level of self-reports of CTA, comparison between the CTA and non-CTA cohorts from Study One reveals that CTA did not appear to adversely affect the health, social or economic outcomes between groups. The reasons for this are complex and highlight the range of interrelated health and social factors that can influence psychological growth, including how resilience is developed and manifested in individuals. Furthermore, as indicated in the health, social and illness data, many participants reside in economic and social conditions where poverty was in evidence or a potential risk. As I have discussed, it is widely acknowledged that people living with a psychotic illness have poorer health than the general population (Burns & Esterhuizen, 2008), and higher rates of obesity (Lorant, Deliege et al. 2003), smoking and substance use also are common (Sim, Swapna et al. 2004). These health and social conditions are replicated in the SHIP study cohort.

These results do not provide strong evidence of specificity of CTA to illnesses such as affective or non-affective psychotic disorders. Indeed, specificity of CTA to the development of illnesses such as schizophrenia has not been clearly established (Chen, Murad et al. 2010). A recent review of the literature indicted little or no difference in the proportion of participants with schizophrenia reporting CTA, except for dissociative identity disorder and PTSD where higher proportions of participants reported abuse (Matheson, Shepherd et al. 2013, Shah, Mackinnon et al. 2014). Similarly, the course of psychosis was not significantly associated with CTA. Analysis of the South Australian SHIP data also reveals that participants with affective psychoses are potentially vulnerable to the effects of CTA regarding their psychosis diagnosis, but less so in the domains of life and psychological functioning. However, although I have not investigated the relationship between CTA and the development of psychosis in this PhD research, it is important to acknowledge the potential link between CTA and the development of psychosis, which needs to be examined in future research.

Stigma can also be a significant social and psychological concern for those with a psychotic illness. Most notably, it can have a deleterious impact on social and psychological health by constraining the capacity to recover from psychosis (Kleim, Vauth et al. 2008). Stigma can hinder contact with family members, friends and the wider community, as well as constraining the overall capacity to build social and intimate relationships. This can affect social engagement and community capacity, which can impede or terminate recovery.

As highlighted in the South Australian SHIP sample, psychosis populations appear to be located predominantly in disadvantaged communities. These communities are often characterised by poor social cohesion (Forrest & Kearns, 2001) and can be fertile

environments for complex social and economic difficulties (Cattell, 2001). Having large populations of people with a psychosis residing in disadvantaged communities may increase the complex and interrelated factors that contribute to, and exacerbate, disadvantage in those communities. Given that health outcomes are the result of the complex relationships between individuals and their social environments, there are clear implications regarding these links and their effects on both individuals and communities. The development of policy and practice that seeks to redress the inequalities created by socioeconomic disadvantage should be an important focus of future mental health ideology and praxis. I will discuss the implications of these issues further in Chapter 8.

#### 4.7.1 Study One- Limitations

There were a number of limitations with Study One. Firstly, histories of CTA were assessed when researchers specifically asked if the participant had experienced any type of CTA. If the participant identified a CTA experience(s), an additional question was asked about the nature and/or type of CTA event(s). While these specific questions allowed for the exploration of any temporal relationships between CTA and clinical markers of psychosis in later life, conversely they also curtailed the type of analyses that could be conducted. Thus, more comprehensive questioning that examined the events and experience(s) of CTA may have allowed for utilisation of more powerful methods of analysis. For example, latent class analysis could have been used to identify previously unobservable subgroups in the context of the experience(s) of CTA within the wider SHIP population. Shevlin and colleagues (2007) employed such an analysis. They determined that psychosis cohorts were more likely to have experienced abuse or sexual molestation in childhood.

Furthermore, with more comprehensive questioning of the experience(s) of CTA during the SHIP interview, a principal component analysis could also have been applied to the sample. Such as analysis could have been used to identify which traumatic and/or adverse events experienced by the SHIP sample. This would have provided the capacity to group together types of CTA into specific categories. This type of categorisation could also be used to determine if certain types of CTA events were associated with an increased risk of social disadvantage, social isolation or other psychological, health and social markers of psychosis. Consequently, all categories of CTA were given the same weighting in the analyses. Alternatively, it could be speculated that certain types of CTA may have had a greater impact on adult clinical outcomes. Finally, instead of utilising a single question related to CTA question, a more detailed examination that considers such issues as the time and impact of the CTA event(s) might have allowed for trajectory modelling. This type of questioning could include linear growth models that may further augment the existing literature related to such areas as the relationship between CTA and the emergence and progression of psychosis (Varese et al. 2012).

Another limitation in Study One concerns the cross-sectional nature of the SHIP data. Prospective longitudinal studies are the most favourable design to examine the kinds of questions explored in this PhD research (Susser & Widom, 2012). Key patterns of association or trends in the SHIP data could have been missed due to the type of analyses employed due to cross-sectional data limitations.

This data also relies on retrospective self-reports of CTA. Consequently, the results from the SHIP data may be affected by recall bias. Furthermore, the data regarding CTA could not be independently verified. Retrospective designs have been widely criticized for reliability and validity; particularly as normal memory processes or subsequent traumatic or adverse events may affect the recall of CTA event(s) (Piolino et al. 2002). However, it should be noted that a number of studies have demonstrated that retrospective reports of

CTA in psychosis populations can be valid, reliable and stable over time (Goodman et al. 1999; Arseneault et al. 2011; Fisher et al, 2011). It has also been suggested that retrospective self-reports regarding CTA are more likely to be biased toward underreporting than exaggeration (Maughan & Rutter, 1997).

During the SHIP interview a number of participants also chose not to answer the question related to the experience(s) of CTA. These refusals could have biased the results, particularly if the refusal was associated with a higher likelihood of having a history of CTA. However, comparison of participants on basic demographic variables indicated no selection bias.

Finally, it should be acknowledged that the recruitment protocol for the SHIP research project could also have potentially biased the results. It is possible that the refusal of some potential participants were unable to engage in the SHIP interview due to either severe illness, homeless, employment or other issues. This may have caused selection bias. Therefore, one cannot discount the possibility that the non-engagement of these potential participants, who may also have the experience(s) of CTA, could have biased the final results extrapolated from the SHIP data.

#### 4.8 Study One Conclusion

In Study One I quantitatively examined a range of health, social and economic factors in the lives of the South Australian SHIP cohort. Study One goes beyond prior research in this field. I accessed a large representative sample of people with a psychotic illness and analysed data on a broad range of variables including demographic characteristics, functioning, clinical profile and physical health. Study One has highlighted that people with psychosis often reside in challenging socioeconomic and health circumstances, which can be exacerbated by the illness and its psychosocial implications. The social and health context I have established in Study One has created a unique framework through which to further investigate the relationship between CTA, psychosis and the role of resilience in the lives of people with the illness.

The following chapter contains the journal paper: 'The physical and psychological manifestation of childhood trauma and/or adversity in people with psychosis'. This paper is currently under review and is re-printed here in its entirety. This paper reviews data from the whole South Australian SHIP cohort and examines the ways that people with the experience(s) of CTA self-report physical and psychological health outcomes. This paper further expands on characteristics of the Study One data analysis and describes a number of ways that CTA can be a contributor to depression in women with psychosis. This paper highlights that there has been very little research into the assessment and treatment of the effects of CTA in adults with psychosis and the findings emphasise that interventions to address the effects of CTA are urgently needed.

Chapter 6 presents the thematic analysis of the Study Two interview data. This chapter provides a detailed description and analysis of the themes from the Study Two interviews. This is followed by Chapter 7, which comprises a reproduced paper titled: 'The physical

and psychological manifestation of childhood trauma and/or adversity in people with psychosis'. This paper is currently under review and it explores the links between psychotic illness and socioeconomic disadvantage and examines the impact of psychosis on poverty, physical health, employment and socioeconomic participation. The paper highlights the links between psychosis, poor health and social disadvantage in people with psychosis living in this region. An overview of the health and social status of a representative psychosis cohort is presented utilising data analysed from Study One. The paper posits that the relationship between psychosis and disadvantage is significant, and is influenced by mental health practice, social policy and community socioeconomic contexts. My co-authors and I make some recommendations in the paper for changes to current mental health practice and future research possibilities that enhance understanding in this area of mental health service delivery.

#### Chapter 5

# The Physical and Psychological Manifestation of Childhood Trauma and/or Adversity in People with Psychosis

#### **Statement of Authorship**

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## Statement of Authorship

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#### **Principal Author**

Name of Principal Author (Candidate)	Shaun Sweeney
Contribution to the Paper	Wrote the main manuscript, conducted the literature review and preliminary analysis of data and wrote the results and the discussion.
Overall percentage (%)	80%
Signature	Date 15-6-15

#### **Co-Author Contributions**

By signing the Statement of Authorship, each author certifies that:

- i. the candidate's stated contribution to the publication is accurate (as detailed above);
- ii. permission is granted for the candidate in include the publication in the thesis; and
- iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Tracy Air
Contribution to the Paper	Supervised preliminary analyses, conducted the analyses of the final model, aided in writing the results section.
Signature	Date 15 · 06 · 2015

Name of Co-Author	Lana Zannettino					
Contribution to the Paper	Assited with evaluating and editing the paper.					
Signature	Date 25.06.15					

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Contribution to the Paper	Supervised development of the work, assisted with data interpretation and manuscrievaluation.
Signature	Date 19/6/5
Please cut and paste additional co-	author panels here as required.

#### 5.1 Abstract

#### **5.1.1** Aims

The link between childhood trauma and/or adversity and risk of psychosis is well known. Our aim was to determine the prevalence of childhood trauma and/or adversity in people who have psychotic disorders and to investigate the association between CTA and a range of social and health measures.

#### 5.1.2 Methods

Participants with psychosis (n=391, 42% male) from the South Australian cohort of the 2010 Survey of High Impact Psychosis study were specifically asked about any experience of CTA. Respondents provided information about education, employment, physical and psychological health.

#### 5.1.3 Results

Males who had experienced CTA were more likely to report a lifetime history of cardiovascular/stroke health issues, migraines and anhedonia. However, females who had experienced CTA were significantly more likely to be in a married/de facto relationship and experience a lifetime history of elevated mood. Physical health measures were not significantly associated with CTA in women.

#### **5.1.4 Conclusions**

There has been very little research into the assessment and treatment of the effects of CTA in adults with psychosis. CTA may contribute to higher rates of self-reported poor physical health in men and is associated with elevated mood in women. Our findings suggest that interventions to address the psychological and health effects of past trauma are urgently needed.

### 5.1.5 Key Words

Childhood Trauma and/or Adversity - Psychosis - Self-Reported Health Status - Gender.

#### 5.2 Introduction

The terminology associated with trauma, adversity and early life stress is often used interchangeably across numerous social and health contexts. In discussing the different interpretations of trauma and adversity, Brown, Cohen et al. (1999) provides a definitive definition of childhood trauma and/or adversity (CTA). It encompasses abuse and neglect: verbal assaults on a child's sense of worth, bodily assaults that pose risk of injury, sexual contact, not providing basic psychological/emotional needs and a failure to provide basic needs (Bernstein & Fink 1998, Browne & Winkelman 2007). CTA is associated with a range of poor health and psychological outcomes (Cutajar et al. 2010) and is linked with the development of psychotic disorders in adulthood (Janssen, Krabbendam et al. 2004, Matheson, Shepherd et al. 2013). In particular, the experience(s) of CTA can lead to high levels of anxiety and is associated with hallucinations, psychological withdrawal, depression, and hopelessness (Lysaker & Salvers 2007). The health and psychosocial outcomes of CTA can vary according to gender, with women being more likely to experience sexual abuse whilst men tend to be subjected to physical abuse and/or bullying (Read, van Os et al. 2005). Additionally, in particular cohorts, such as adult women in drug treatment services, as many as 62 per cent to 81 per cent report the experience of CTA (Teets 1995, Gil-Rivas, Fiorentine et al. 1997, Liebschutz, Savetsky et al. 2002).

Estimates of the rates of CTA worldwide indicate that every year millions of children experience trauma and/or adversity, including physical, sexual, and emotional abuse, and severe neglect (Krause, 2008). Research indicates that most people are exposed to at least one psychologically or physically traumatic event during their lifetime (Pineles, Mostoufi et al. 2011). Other studies have demonstrated that, on average, an individual experiences nearly three traumatic or adverse events during their life (Alim, Feder et al. 2008). Additionally, estimates of the rates of trauma worldwide indicate that every year millions

of children experience CTA, including abuse and/or neglect (Norris 1992, Krause 2008). An increasing number of children and adolescents have also been victims of natural disasters, such as Hurricane Katrina in 2005, which displaced more than one million people (Akin-Little & Little 2008). Differences in the experience of types of trauma across genders are also evident in the research. Numerous studies have demonstrated that females are more likely to experience interpersonal assaults such as rape and sexual abuse in childhood or adulthood (Breslau, Davis et al. 1997, Breslau, Kessler et al. 1998, Perkonigg & Wittchen 1999). This has also been found in psychotic patients. For example, Schenkel and colleagues found that 47 per cent of females in their sample had experienced childhood CSA, compared to 16 per cent of males (Schenkel, Spaulding et al. 2005). Kilcommons and Harrison (2005) reported that 14 per cent of females in their sample had experienced CSA versus 12 per cent of males, while Goodman and colleagues (Goodman, Salvers et al. 2001) reported rates of CSA in females of 49 per cent, and 29 per cent in males. Finally, Read et al. (2005) reviewed 51 studies conducted between 1987 and 2005 and found high rates of childhood sexual and physical abuse among psychotic patients: sexual abuse (48% of females and 28% of males) and physical abuse (48% of females and 50% of males).

For those with a history of CTA and who have developed a psychotic disorder, the combination of a serious mental illness and the challenge of living with the psychological effects of CTA can make health, economic, and social functioning extremely difficult (Spataro, Mullen et al. 2004). While research has been conducted into the influence of CTA, particularly child sexual abuse on health, psychological and social functioning in female populations, CTA in male cohorts has received less attention. This is possibly due to its lower rates of prevalence and less overt symptomatic presentation(s). There is also widespread evidence that psychosis is correlated with poor physical health, lower levels of

educational attainment and poorer socioeconomic outcomes (Lund, Breen et al. 2010). Additionally, people with psychosis can also exhibit higher rates of obesity (Taylor, McIntyre et al. 2012), illness comorbidity (Sim, Swapna et al. 2004), and substance abuse than in the general population (Addington & Addington 2007).

Despite an extensive collection of research into the effects of psychosis on many of the domains of life there has been little exploration of the physical impact of CTA on people living with psychosis. The present study took place in the northern region of Adelaide, South Australia. This is a disadvantaged region with a high proportion of people in receipt of government benefits, high unemployment rates, lower levels of education, and high rates of mental health (Ahern, Kiehl et al. 2006). Within this adverse socioeconomic environment, our aim was to determine the prevalence of CTA in people who have psychotic disorders, and to investigate the associations between CTA and a range of psychiatric, social, and health measures. Given that gender differences in both the nature and adult consequences of CTA were likely, we undertook separate analyses for men and for women. It would be expected that co-existing CTA and psychosis would be associated with a poorer outcome than psychosis alone. We expected participants who experienced CTA to have left school earlier, be more likely to be unemployed and to have poorer economic functioning. We expected that both their self-reported physical and psychological health would be worse. These assumptions are based on evidence in the literature indicating the correlation between CTA and lower socio-economic status and poor health compared to non-CTA populations (Raphael, Widom et al. 2001, Frederick & Goddard 2007, Nikulina, Widom et al. 2011).

#### 5.3 Materials and Methods

#### 5.3.1 Subjects

The data for this study was collected during the Second Australian Survey of Psychosis 2010 research project (Morgan, Waterreus et al. 2012). Trained interviewers, who were mental health clinicians and had worked in the local mental health services, conducted all of the interviews. The appropriate institutional ethics committees approved the study and all participants gave written informed consent. Further information regarding the method of the Second Australian Survey of Psychosis 2010 is detailed in Morgan et al. (2013).

A screening instrument for psychosis identified 1702 adults aged 18–64 years who were residents in the South Australian catchment postcodes. These potential participants had been in contact with public mental health services in the 12 months prior to the survey and attempts were made to recruit all of these potential participants. Eight hundred and three were unable to be contacted, 16 had died, 33 did not meet inclusion criteria due to inability to sufficiently communicate in English, 42 did not have capacity to give informed consent, and 507 refused. Of the 402 SHIP in the South Australian cohort, 232 self-reported the experience(s) of CTA. Eleven participants chose not to answer the CTA question and were excluded, leaving a study population of 391 participants. This represents 57 per cent of the entire South Australian SHIP cohort. No significant differences were found between those excluded due to missing CTA data and the included participants on gender, age, diagnosis and education. Demographic data was collected for all participants. Diagnoses were made using the Diagnostic Interview for Psychosis (DIP) (Castle, Jablensky et al. 2006). CTA identification was made in response to questions referring to Socialising, Social Isolation and Social Withdrawal section of the SHIP interview schedule (question-9.08) that asked: "Were there any distressing of traumatic events in your childhood, Yes/No". The type of CTA experienced was also asked.

For the SHIP research a two-phase design was employed (Pickles, Dunn et al. 1995). This design was appropriate for estimating the prevalence of a relatively uncommon disorder and was regarded as efficient in identifying those likely to meet diagnostic psychosis criteria for which the full interview schedule was relevant.

In Phase 1, screening for psychosis took place in public specialised mental health services. A screening instrument was utilised to identify potential participants in the SHIP project. The Psychosis Screen (PS) is a brief screening questionnaire to classify people who have been diagnosed with a psychotic disorder (schizophrenia, schizoaffective disorder, affective disorder with psychotic features, delusional disorder, psychosis due to substance or alcohol abuse, organic brain disease, or general medical disease). The screening questionnaire was developed for the first national psychosis survey originally conducted in 1997 (Jablensky, McGrath et al. 2000). In Phase 2, potential participants who were screened positive for psychosis in Phase 1 were then randomly selected and stratified by age group (18–34 years and 35–64 years) for interview and assessment.

#### **5.4 Ethics Statement**

Ethics approval for this research was obtained from the Human Research Ethics Committee of the Queen Elizabeth Hospital (Protocol number: 2009179). Participants provided written consent to participant in the study. They were asked to sign a consent form and a copy was provided to keep for their own record. The Human Research Ethics Committee of the Queen Elizabeth Hospital approved this consent procedure.

#### 5.5 Assessments

The Second Australian Survey of Psychosis 2010 interview schedule was comprised of 32 modules, including the Alcohol Use Disorders Identification Test (Babor, Higgins-Biddle

et al. 2001), the World Health Organization Schedules for Clinical Assessment in Neuropsychiatry (Kirkpatrick, Buchanan et al. 1989, World Health Organization 1999). The details for all other measures are described in Morgan et al. (Morgan, Waterreus et al. 2012).

#### 5.6 Childhood trauma and/or adversity

Questions about the occurrence and nature of CTA were included in the interview. The SHIP interview schedule rated the incidence(s) of CTA using a self-reported item on CTA in the childhood adversity module. CTA identification was made in response to questions referring to Socialising, Social Isolation and Social Withdrawal. In Australia, all states follow a national framework of guidelines for defining the four types of child abuse (a) sexual abuse (b) physical abuse (c) emotional abuse (d) neglect (World Health Organisation, 2012). The classification of reported CTA was undertaken in collaboration with staff from the Western Australian Department of Child Protection to ensure conformity to national guidelines.

Two raters independently coded each response. Agreement between the two coders was 96 per cent; a consensus decision was reached on remaining items. This paper includes only those cases where the CTA is consistent with the standard Australian definitions (Bromfield & Holzer 2008), took place when the participant was aged 18 years or younger, and occurred prior to the onset of psychotic illness.

#### **5.7 Statistical Analyses**

Statistical analyses were performed using Stata, version 12 (StataCorp. 2011. Stata Statistical Software: Release 12. College Station, TX: StataCorp LP). Potential demographic, physical and psychological health correlates of CTA were chosen after reviewing the literature. They were grouped into three categories: demographics (Table

5.1), physical symptoms (Table 5.3) and psychological symptoms (Table 5.4). A two-step model building procedure was used to determine variables associated with CTA. In the first step, we used univariate analyses (chi-squares and t-tests) to examine relationships between CTA and the independent variables. As the incidence of CTA was much higher in females, these analyses were also stratified to explore gender specific associations. Effect size measures (Cohen's d) relating to the difference between CTA and No CTA group were also determined. As the univariate tests were being used to inform the larger model, and also due to the exploratory nature of this study, corrections for multiple comparisons were not performed. In the second step, significant variables from each block were entered into a model. These analyses were also stratified by gender. In the final stratified model, the non-significant variables were removed, and the authors report the significant predictors, while controlling for age and possible confounders of health status, such as lifetime histories of smoking, heavy alcohol usage and cannabis use.

#### 5.8 Results

Of the 391 participants, 59.3 per cent of reported experiencing CTA. CTA was reported more in females than males ( $\chi$ 2=19.7, df=1, p<0.001). Table 5.1 depicts the sociodemographic characteristics of the sample. Participants who had experienced CTA were more likely to be married or living in a de facto relationship ( $\chi$ 2=13.2, df=2, p=0.001), and had left school earlier (t=-3.22, df=389, p=0.001). There was no difference in diagnosis or in rates of lifetime smoking, lifetime history of heavy alcohol use, or cannabis use, between those with and without CTA. The largest portion of the 232 participants who had experienced CTA met criteria for an ICD-10 diagnosis of schizoaffective disorder (34.5%), while 25.9 per cent had been diagnosed with schizophrenia. This observation was reversed in the non-CTA group, where 40 per cent screened positive for schizophrenia, and 27.2 per cent were diagnosed with schizoaffective disorder. There were no significant differences in ICD-10 diagnoses between the CTA and non-CTA groups. Between group effect sizes

indicated a medium effect for gender, and small-medium effect sizes for age left school and marital status.

Table 5.1: Socio-demographic and diagnostic data and course of disorder for people with psychosis, comparing those who had experienced CTA with those who had not

	C	ГΑ	No	CTA	T	otal (		Cohen's
	(n=	232)	(n=	159)	(n=	=391)	p	d
Age and Sex								
Female (n, %)	118	50.9	45	28.3	163	41.7	< 0.001	0.54
Age (mean±SD, years)	39.1	10.2	37.5	11.1	38.4	10.5	0.16	0.14
Age left school (mean±SD,	15.8	1.3	16.3	1.2	16.0	1.3	0.001	-0.39
years)								
Marital Status (n, %)								
Single	106	45.7	102	84.6	208	53.2	0.001	0.32
Married/defacto	59	25.4	24	15.1	83	21.2		
Currently separated, divorced,	67	28.9	33	20.8	100	25.5		
widowed								
Lifestyle Factors								
Lifetime smoking	197	84.9	138	87.3	335	85.9	0.50	-0.11
Lifetime heavy alcohol usage	145	67.1	92	63.5	237	65.6	0.47	0.09
Lifetime cannabis usage	167	72.0	113	71.5	280	71.8	0.92	0.01
Income (n, %)								
Main income source: pension	212	91.8	147	93.0	359	92.3	0.65	-0.12
Duration of illness (years)	15.3	10.0	13.2	9.4	14.4	9.8	0.043	0.22
Employment (n, %)								
Paid Employment (past year)	54	23.3	38	23.9	92	23.5	0.89	-0.02
ICD-10 diagnosis (n, %)								
Schizophrenia	60	25.9	63	40.0	123	31.5	0.09	0.14
Schizoaffective	80	34.5	43	27.2	123	31.5		
Bipolar, mania	45	19.4	22	13.9	67	17.2		
Depressive psychosis	12	5.2	6	3.8	18	4.6		
Delusional and other non- organic psychoses	14	6.0	9	5.7	23	5.9		
Severe depression	21	9.1	15	9.5	36	9.2		

#### 5.7.1 Types of trauma and/or adversity experienced by the sample

Table 5.2 depicts the different types of trauma experienced by the sample, stratified by gender. CSA and abuse/neglect were the most commonly reported childhood traumas. Compared with men, significantly more women reported sexual abuse ( $\chi$ 2=26.46, df=1, p<0.001). There were no other significant differences between the genders on any other of the trauma categories.

**Table 5.2: Types of CTA reported by participants** 

СТА Туре	CTA (n=	Men (n=114)		Women (n=118)		
	n	%	n	%	n	%
Sexual abuse	69	29.7	16	14.0	53	44.9
Abuse/Neglect	62	26.7	31	27.2	31	26.3
Bullied	17	7.3	12	10.5	5	4.2
External experience of death	15	6.5	11	9.7	4	3.4
Accident/Injury	11	4.7	7	6.1	4	3.4
Poor Health	7	3.0	3	2.6	4	3.4
Domestic Violence	6	2.6	5	4.4	1	0.9
Parental Divorce/Separation	6	2.6	4	3.5	2	1.7
Other *	39	16.8	25	21.9	14	11.9
Total	232	100	114	49.1	118	50.9

• Other- loss, single traumatic events

#### 5.7.2 Physical and psychological health

The CTA group generally indicated higher rates of reported lifetime physical health conditions (Table 5.3). More of the CTA positive group experienced chronic pain ( $\chi 2=18.24$ , df=1, p=0.001), headaches/migraines ( $\chi 2=19.73$ , df=1, p=001), arthritis ( $\chi 2=10.88$ , df=1, p=0.001) and asthma ( $\chi 2=5.52$ , df=1, p=0.019). Cardiovascular disease and/or stroke was also more common in the CTA positive group ( $\chi 2=9.80$ , df=1, p=0.002). Overall, between group effect sizes indicated medium effects for cardiovascular disease/stroke, arthritis and migraines, and a small-medium effect size for asthma. More males with a history of CTA than expected reported chronic pain ( $\chi 2=5.2$  df=1, p=0.022), cardiovascular disease/stroke ( $\chi 2=7.9$  df=1, p=0.005), headaches/migraines ( $\chi 2=10.0$  df=1, p=0.001), arthritis ( $\chi 2=4.7$  df=1, p=0.031) and epilepsy ( $\chi 2=5.3$  df=1, p=0.021). In men, between group effect sizes indicated medium effect sizes for cardiovascular disease/stroke, headaches/migraines, arthritis and epilepsy. More females with CTA than expected reported chronic pain ( $\chi 2=9.8$  df=1, p=0.002) and headaches/migraines ( $\chi 2=6.2$  df=1, p=0.012). In women, a medium effect size was found for headaches/migraines.

**Table 5.3: Lifetime physical conditions** 

	C	ГА	No	CTA	To	otal		Cohen's
	(n=	232)	(n=	159)	(n=	391)	р	d
Lifetime Physical								
conditions (n, %)								
Asthma	81	34.9	37	23.7	118	30.4	0.019	0.30
Cardiovascular/Stroke	54	23.5	17	10.9	71	18.4	0.002	0.51
Severe	89	38.4	27	17.3	116	29.9	< 0.001	0.60
headaches/migraines								
Arthritis	64	27.6	21	13.5	85	21.9	0.001	0.49
Diabetes	56	24.5	39	25.2	95	24.7	0.88	-0.02
Epilepsy	25	10.8	10	6.5	35	9.0	0.15	0.31
Cancer	11	4.7	4	2.6	15	3.9	0.28	0.35
Males (n, %)								
Asthma	33	29.0	24	21.2	57	25.1	0.18	0.23
Cardiovascular/Stroke	27	23.7	11	9.7	38	16.7	0.005	0.58
Severe	39	34.2	18	15.9	57	25.1	0.001	0.56
headaches/migraines								
Arthritis	20	17.5	9	8.0	29	12.8	0.031	0.50
Diabetes	26	23.2	24	21.4	50	22.3	0.75	0.06
Epilepsy	18	15.8	7	6.2	25	11.0	0.021	0.58
Cancer	2	1.8	3	2.7	5	2.2	0.64	-0.23
Females (n, %)								
Asthma	48	40.7	13	30.2	61	37.9	0.23	0.25
Cardiovascular/Stroke	27	23.3	6	14.0	33	20.8	0.20	0.34
Severe	50	42.4	9	20.9	59	36.7	0.012	0.56
headaches/migraines								
Arthritis	44	37.3	12	27.9	56	34.8	0.27	0.24
Diabetes	30	25.6	15	34.9	45	28.1	0.25	-0.24
Epilepsy	7	5.9	3	7.1	10	6.3	0.78	-0.11
Cancer	9	7.6	1	2.3	10	6.2	0.21	0.69

The CTA positive group experienced different rates of lifetime psychological symptoms than the non CTA group (Table 5.4). For example, the CTA group were more likely to report a lifetime history of depressive mood ( $\chi$ 2=7.96, df=1, p=0.005), anhedonia ( $\chi$ 2=14.30, df=1, p=0.001), poor concentration ( $\chi$ 2=4.67, df=1, p=0.031), elevated mood ( $\chi$ 2=5.16, df=1, p=0.023). However the non CTA group were more likely to report a lack of insight ( $\chi$ 2=5.68, df=1, p=0.017). Males with CTA also were more likely to have experienced anhedonia ( $\chi$ 2=8.44, df=1, p=0.004) and subjective thought disorder ( $\chi$ 2=3.87, df=1, p=0.049). Conversely, females with CTA were more likely to have reported depressive mood symptoms ( $\chi$ 2=5.59, df=1, p=0.018) and elevated mood symptoms ( $\chi$ 2=4.30, df=1, p=0.038).

**Table 5.4: Psychological symptoms: lifetime** 

	C	ΓΑ	No	CTA	T	otal		Cohen's
	(n=2)	232)	(n=	159)	(n=	391)	p	d
Lifetime symptoms (n,								
%)								
Delusions	213	91.8	148	93.1	361	92.3	0.64	-0.10
Hallucinations	194	83.6	135	84.9	329	84.1	0.73	-0.05
Subjective thought	159	68.5	94	59.1	253	64.7	0.06	0.23
disorder	212	01.4	120	01.0	2.42	07.5	0.005	0.47
Depressed mood	212	91.4	130	81.8	342	87.5	0.005	0.47
Anhedonia	203	87.5	115	72.3	318	81.3	< 0.001	0.54
Suicidal Ideation	171	73.7	105	66.0	276	70.6	0.10	0.20
Poor concentration	179	77.2	107	67.3	286	73.2	0.031	0.27
Irritable Mood	87	37.5	55	34.6	142	36.3	0.56	0.07
Elevated Mood	110	47.4	57	35.9	167	42.7	0.023	0.26
Lack of insight	47	20.3	49	30.8	96	24.6	0.017	-0.30
Males (n, %)								
Delusions	105	92.1	105	92.1	210	92.1	1.00	0.00
Hallucinations	95	83.3	99	86.8	194	85.1	0.46	-0.15
Subjective thought	83	72.8	69	60.5	152	66.7	0.049	0.31
disorder								
Depressed mood	98	86.0	91	79.8	189	82.9	0.22	0.24
Anhedonia	95	83.3	76	66.7	171	75.0	0.004	0.51
Suicidal Ideation	84	73.7	76	66.7	160	70.2	0.25	0.19
Poor concentration	77	67.5	73	64.0	150	65.8	0.58	0.09
Irritable Mood	35	30.7	36	31.6	71	31.1	0.89	-0.02
Elevated Mood	44	38.6	40	35.1	84	36.8	0.58	0.08
Lack of insight	26	22.8	38	33.3	64	28.1	0.08	-0.29
Females (n, %)								
Delusions	108	91.5	43	95.6	151	92.6	0.38	-0.38
Hallucinations	99	83.9	36	80.0	135	82.8	0.56	0.15
Subjective thought	76	64.4	25	55.6	101	62.0	0.30	0.20
disorder	, 0	0		00.0	101	02.0	0.50	0.20
Depressed mood	114	96.6	39	86.7	153	93.9	0.018	0.81
Anhedonia	108	91.5	39	86.7	147	90.2	0.35	0.31
Suicidal Ideation	87	73.7	29	64.4	116	71.2	0.33	0.24
Poor concentration	102	86.4	34	75.6	136	83.4	0.10	0.40
Irritable Mood	52	44.1	19	42.2	71	43.6	0.10	0.40
Elevated Mood	66	55.9	17	37.8	83	50.9	0.83	0.04
	21	33.9 17.8	17	37.8 24.4	32	30.9 19.6	0.038	-0.22
Lack of insight	21	1/.8	11	∠ <del>4</del> .4	32	19.0	0.34	-0.22

#### 5.7.3 Physical and psychological health profile

Table 5.5 displays the results of the final multiple logistic regression model for the prediction of CTA in men and women independently. Most of the physical and psychological health variables that had been significant in the univariate analyses were no longer so in the multivariate models for either gender. However, males who had experienced CTA were more likely to report experiencing a lifetime history of cardiovascular/stroke health issues, migraines and anhedonia. Conversely, females who had experienced CTA were significantly more likely to be in a married/de facto

relationship and a lifetime history of elevated mood. The physical health measures were not significantly associated with CTA.

Table 5.5: Relationship between CTA and demographics, psychological and physical health profiles in people with psychosis, stratified by sex

	M	ales		Fe	emales	
	OR	95% CI	p	OR	95% CI	p
Age at interview	0.98	0.9-1.0	0.36	1.04	0.9-1.1	0.29
Marital status						
Single, never married	Referei	nce group		Refere	ence group	
Married/defacto	-			4.89	1.2-19.2	0.02
Currently separated, divorced,	-			2.05	0.6-7.5	0.28
widowed						
Lifetime history of smoking	0.41	0.1-2.6	0.34	1.24	0.6-27.3	0.89
Lifetime history of heavy alcohol use	1.43	0.7-3.0	0.34	1.39	0.4-4.4	0.57
Lifetime history of cannabis use	0.93	0.9-1.0	0.07	1.07	0.9-1.2	0.18
Psychological symptoms						
Anhedonia	2.70	1.2-5.9	0.012	-		
Elevated Mood	-			4.11	1.38-12.2	0.01
Physical Symptoms						
Cardiovascular/Stroke	4.18	1.5-11.8	0.007	-		
Migraines	3.08	1.2-7.1	0.008	-		

#### 5.8 Discussion

Our study accessed a large representative sample of people with psychotic illness living in a disadvantaged region of urban Adelaide, South Australia. Overall, prevalence of CTA was high, with nearly 60 per cent of participants reporting physical, sexual and/or emotional abuse and neglect. This is consistent with the association between CTA and adult psychotic disorders (Morgan & Fisher 2007, Matheson, Shepherd et al. 2013). Research has demonstrated the CTA can have long lasting psychological and social implications. This includes increased incidence of psychiatric disorders (Lindert, von Ehrenstein et al. 2014), physical health disorders (Stesssman, Cohen et al. 2008, Acierno, Hernandez et al. 2010) and psychological difficulties (Min, Farkas et al. 2007). For example, children raised in dysfunctional or abusive environments are more likely to use alcohol and/or drugs (Lynch, Kaplan et al. 1997, Felitti, Anda et al. 1998). In our study sample, participants with a CTA history left school earlier, perhaps due to difficulties in

their home and personal lives. Rates of employment did not differ from those who did not report CTA. Unlike general population samples where CTA is associated with higher rates of substance use (Dube, Felitti et al. 2003), the CTA cohort in our sample did not replicate this research. Further, the CTA cohort was more likely to be married and have children, suggesting the capacity to form intimate relationships. The possible reasons for this are psychosocial and socioeconomically complex. For example, while traumatised or abused individuals often form relationships with others who have experienced similar life events (Basham & Miehls 2004), these relationships may be of a more dysfunctional nature. Nonetheless, despite the experience of CTA, the participants in our sample appear to have demonstrated the capacity to form relationships. However, our research is limited in that we have not assessed the functional dynamics of the relationship. It is possible that the CTA group may be confined to engaging in dysfunctional relationships possibly due to their limited psychological and social resources.

As discussed, considerable research has been conducted into the effect of CTA on health, psychological and social functioning in the general population. This includes the association between CTA and physical illnesses such as cardiac, respiratory and gastrointestinal diseases as reported in community samples (Goodwin & Stein 2004). For example, some studies have reported a relationship between CTA and cardiovascular disease (Galobardes, Smith et al. 2006), obesity (Heraclides, Witte et al. 2008) and diabetes (Maty, Lynch et al. 2008). Furthermore, there are an increasing number of studies investigating gender differences and the consequences of CTA on health. Irving and Ferraro (Irving & Ferraro 2006) reported that childhood emotional abuse was predictive of worse self-rated health in females. The risk of obesity, diabetes and cardio-vascular events has been found to be related the CTA in females but not in male samples (Hamil-Luker & Angela 2007, Maty, Lynch et al. 2008, Khlat, Jusot et al. 2009). Other studies have found

stronger associations in males (Taylor, Lerner et al. 2004). However, the relationship is less clear in male psychosis populations, as the authors were unable to find and other research in this topic to date. For male populations, the high rate of the self-reporting of physical illness in male psychosis populations such as ours may be an indicator of a CTA history. The self-reported poorer physical health, which was more prominent in men, may reflect somatic expression of emotional distress, or poorer self-care with greater vulnerability to physical illness. Most significantly, physical illness in males with psychosis, particularly those with first episode psychosis, may be a manifestation of an undisclosed CTA experience(s). Self-reported health risks can potentially compound the already high health, psychological and social burden associated with psychotic illness for this population. These represent deficits that can exacerbate the psychological burden of the experience(s) of CTA.

Most intriguing is the finding that CTA may influence and potentially compromise health functioning among adults with psychosis. Despite this, there has been very little research into the assessment and treatment of the effects of CTA in adults with psychosis. Thus, there are some unanswered questions about the role of CTA in the symptoms and outcomes of men with psychosis and this awaits future research. Further research is also needed to determine the extent to which the relationship between CTA and health and psychosocial functioning is moderated by other intervening variables, such as cognitive function, substance abuse, and illness symptomology in psychosis populations.

A significant portion of non-psychosis trauma in the literature links CTA to deficits in areas such as psychological and social functioning (Mulvihill, 2005) as well as health functioning (Norman, Means-Christensen et al. 2006). Nonetheless, CTA our sample unexpectedly did not replicate this association, either at a univariate or multivariate level

of analysis. Our findings suggest that interventions are urgently needed. These challenges highlight the importance of an integrated approach to mental health and community based service provision. Such an approach may help to ensure that people with psychosis and the experience(s) of CTA have their health and social needs met in ways that can enhance their illness recovery. Answers to these questions will help in better understanding the processes surrounding health and psychosocial functioning in psychosis populations and to develop and deliver more effective clinical treatments. The population-level data collected as part of the 2010 SHIP research provide a solid empirical foundation to guide health and social policy development and the provision of mental health services regarding many aspects of psychosis/CTA populations.

#### 5.9 Limitations

This study has a number of important limitations. Given the univariate findings did not translate into complex multivariate explanatory models, it could be that the design of the study does not adequately represent the myriad of health, psychological and socioeconomic challenges of the SHIP cohort. Although we were able to explore the temporal relationship between self-reported physical health and clinical outcomes in adulthood, we were unable to determine severity, frequency, duration and perpetrator of the abuse due to the interview design. Therefore, we may have missed important patterns of association. In addition, we acknowledge that longitudinal studies that collect CTA data prospectively are the optimal design for this type of research.

As our data rely on retrospective self-report, the accuracy may be affected by recall bias. However, a number of studies have demonstrated the validity and reliability of retrospective reports of trauma in psychosis populations. These studies indicated that reports of CTA are stable across time, unaffected by current symptoms, and generally correlate well with other sources of information (Arseneault, Cannon et al. 2011).

Additionally, there is evidence that the retrospective assessment of child abuse tends to underestimate rather than over-report real rates, possibly due to poor memory, denial, or embarrassment. Consequently, our data may underestimate the strength of the relationship between CTA and subsequent outcomes.

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#### **5.11 Conflict of Interest**

The authors report no conflicts of interest. The authors alone are responsible for the content and the writing of this article.

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#### Chapter 6

**Study Two: Thematic Analysis** 

#### 6.1 Introduction

This chapter examines the themes that emerged from the analysis of the Study Two interview data. As I described in Chapter 3, the use of a thematic analysis allows for the identification and analysis of themes within an interpretive framework. The process provided insights into the 'reality' (Braun & Clarke 2006, p.81) of participants' understandings of psychosis, CTA and resilience. It highlighted the interrelated social, psychological and health factors that shape the lives of participants. This thematic analysis of the face-to-face interview data also provided scope to explore the role of resilience in the lives of people with the lived experience of psychosis and CTA.

#### **6.1.1 Study Two Interviews**

During the Study Two interviews I asked participants to describe their experiences of psychosis and to consider the influence of CTA in their lives. I also asked participants about their understandings of resilience. Across the sample, responses to the interview questions provided a range of observations, personal insights and understandings about the topics. I explored these in the context of participants' experiences of psychosis and CTA. During the interview process, the majority of participants were open, insightful and lucid when recounting their personal experiences, insights and views. However, some were also occasionally guarded in their responses. A small number of participant accounts were fragmented, brief (particularly when discussing topics related to CTA), or occasionally contradictory in nature.

As I stated in Chapter 3, I organised the qualitative data generated from these interviews into specific themes using NVivo 9 software. I utilised NVivo 9 software specifically for the data analysis to categorise the personal insights of participants into specific themes. I scrutinised each participant interview for content and consequently allocated the content to a specific theme. Themes emerged as I categorised the content of the interviews. A thematic picture with clearly defined themes and sub-themes emerged from this analysis.

#### **6.1.2 Thematic Structure**

Four primary themes emerged from the data analysis process and they delineate the Study Two thematic framework. Additionally, each of these four primary themes includes several sub-themes. These themes evolved through a continual process of the analysis, interpretation and refinement of the interview data. This process ensured that theme identification was not confined by the initial interview questions. A thematic schema is provided at the beginning of each sub-section of this chapter. This schema is intended to provide a guide to the themes and sub-themes explored in each section of the chapter. Figure 6.1 illustrates the overall thematic structure of the analysis of the Study Two interview data.

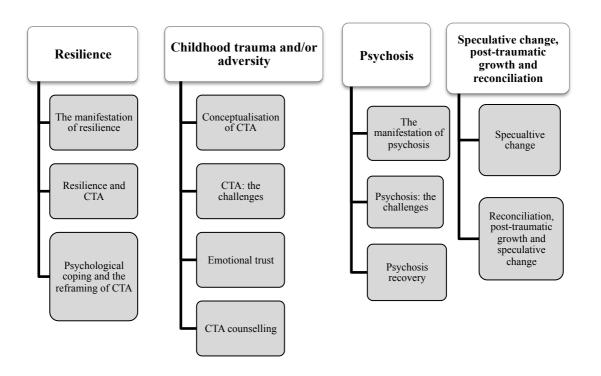


Figure 6.1: Thematic Structure for Study Two

#### 6.1.3 The Study Two Cohort: Demographics and CTA Histories

Twenty-seven people participated in Study Two. Eighteen were female (66.7%). The mean age of the interview group at the time of the SHIP interview was 37.6 years (SD=34.0). The mean age of the Study Two group at the time of the CTA event was 8.2 years (SD=7.7, range 2-16). Nine participants (33%) reported a history of CSA, six (22%) a history of other traumatic and/or adverse childhood experiences (e.g. physical abuse, neglect, being bullied). Two (7%) experienced bullying while nine (40%) reported CTA types listed in the 'other' category. 18

#### 6.1.4 Resilience and the Measure of Resilience: The Resilience Scale

As I discussed in Chapter 3, I asked Study Two participants to complete the Resilience Scale (Wagnild & Young, 1993), a quantitative measure of resilience that was administered during the face-to-face interviews. The Resilience Scale is one of the more

<sup>18</sup> Other CTA types include family anger, family alcohol abuse, physical accident, experience of

bullying, etc.

commonly utilised and accessible quantitative measures of resilience. Twenty-one participants agreed to complete the measure. The primary purpose of utilising the Resilience Scale was to provide additional quantitative data about participants' self-assessments of their resilience levels and capacity for psychological coping.

The items included in the Resilience Scale included questions such as: 'I am able to adapt when changes occur', 'I am determined', and 'I can get through difficult times because I've experienced difficulty before' (see Appendix 5 for a reproduction of the Resilience Scale). Participants were asked to rate items on a scale from 1 ('Strongly Disagree') to 7 ('Strongly Agree'). Despite complex social and health challenges in the lives of Study Two participants, resilience was evident in a significant portion of the cohort. The majority of participants self-reported that they perceived themselves as having some level of resilience. Table 6.1 details the Resilience Scale scores for Study Two participants, highlighting how they individually self-assessed their resilience.

Table 6.1: Resilience Scale (RS) Study Two participant scores

ID number	RS total score	RS category
1117	na	
1136	na	
1140	na	
1225	177	very high
1228	148	high
1233	na	
1385	151	high
1400	na	
1406	170	very high
1448	224	very high
1468	na	
1469	112	low
1472	82	low
1496	139	moderately high
1530	105	low
1543	126	moderately low
1546	130	moderately high
1590	142	moderately high
1608	68	low
1633	157	high
1645	121	moderately low
1686	147	moderately high
1688	158	high
1751	143	moderately high
1791	151	high
1839	122	moderately low
1930	150	high

**Mean** = 139 (moderate resilience)

#### 6.2 Theme One: Resilience

Resilience means to me; like tough. (1608)

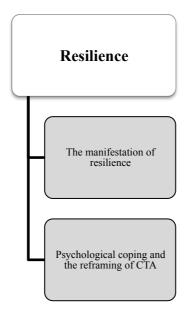


Figure 6.2: Thematic Structure of Theme One

#### **6.2.1 Introduction**

The first major theme and associated sub-themes summarise participants' personal accounts of resilience. These accounts include a number of insights and beliefs about the effect of CTA on the development of their resilience. There was consistency in these accounts across the sample. The primary theme is titled 'Resilience'. The sub-themes include 'Manifestation of Resilience' and 'Psychological Coping and the Reframing of CTA'. All of these themes are interconnected. They consolidate participants' insights about resilience and CTA as a factor in the development of their resilient selves. Of note, the majority of Study Two participants framed resilience within the context of illness symptomology and recovery.

#### **6.2.2** The Manifestation of Resilience

Participants provided a diverse range of examples and individual insights about resilience.

Despite this, a collective understanding about the importance of resilience as a contributor

to emotional health and functioning emerged from the interview data. While there was individual variation in participants' interpretations of resilience, there were clear agreements across the Study Two cohort regarding its behavioural and emotional dimensions.

Participants predominantly described the notion of resilience as the ability to 'cope' (1045) and to 'bounce back' (1686) from psychological or emotional challenges. For example, one participant described a resilient person as:

Someone who has experiences and they can be extremely challenging or rewarding, but they are resilient as in they still continue to go on the path that they are going on and they bounce back quite well. And just keep on flowing on where they are meant to do, so fall down, or have an event in life that can be major or minor, but they continue with daily routines in life and relationships. (1448)

Aligned with this interpretation of resilience was the notion of overcoming difficult or adverse life experiences:

I've had triumphs and I've had setbacks. I overcome the setbacks. I get frustrated sometimes and I think 'to hell with it' and then I regroup, I re-think and then I go forward again. (1751)

The concept of psychological strength – 'it means to me like tough' (1608) – was at the core of numerous participants' interpretations of resilience. For example, one participant described themself as:

A very strong person. Very strong willed and that has what has got me through. (1385)

Another participant similarly referred to inner strength that they accessed to overcome setbacks as comprising a strong resilient self:

I guess there's a strong inner me that I can just talk to myself and sort of say, 'hey, this is only temporary'. You know, that inner voice, that inner strength that I draw on, telling myself this is only temporary. (1791)

Participants also believed that being self-confident, including the ability to be assertive and autonomous, constituted a psychologically resilient self:

I just don't give in anymore. I stand up now. I'm sick of people walking all over me. (1255)

Another participant stated that:

nobody has the right to make me feel anything that I don't want to feel. You know that's the coping mechanism I learnt as a child. (1140)

The majority (82%) of participants concluded in the interview that they had some level of resilience, with one noting that they were '*learning to be more resilient*' (1751). Some perceived resilience as an established part of their identity that defined their personalities. This was indicated in statements such as:

I've always been resilient. I've coped with a lot of things in my life ... it's [resilience] what I do and what I am. (1400)

In a number of interviews, participants expressed feelings of accomplishment in their ability to remain psychologically robust and able to 'overcome' (1751) despite seemingly overwhelming obstacles. While two participants assessed their own resilience level as low when completing the Resilience Scale, they still perceived resilience as central to notions of their preferred self:

I'm not that resilient; too much crap at the moment, which bugs me because I like to be resilient and to be there and this and that, because if I haven't got the resilience then I'm not who I am. (1496)

Literature in the field of resilience suggests that some people potentially derive psychological benefits from successfully adapting to traumatic, adverse or stressful experiences. These benefits include positive changes in self-concept and relationships with others, the enhancement of personal growth, and the alteration of life priorities (Updegraff, 2000). Reflecting Updegraff's observations, a number of participants (n=7) described how they had rationalised and integrated their past CTA experience(s) within their lives and had become emotionally more resilient. For some, the experience(s) of CTA were fundamental to establishing and defining their sense of their own identity:

That massive, massive catastrophic event [CTA] that happened in my life has made me who I am today. (1140)

Another participant similarly focused on the influence of CTA on their life trajectory and identity:

I can't imagine it not having happened now. I wouldn't be the same person. I wouldn't have the same job, the same people in my life, I wouldn't be as close to my family, I wouldn't be as resilient, a lot of things that have come out of that have been beneficial. If I hadn't had the experience I wouldn't be the peer worker<sup>19</sup> I am today. (1136)

One participant similarly linked the development of their resilience to the personal experience(s) of CTA. They cited increased self-awareness and empathy for others as aspects of their resilience:

I suppose if I hadn't had too much trauma, I would be less resilient. I really do.

I would be less resilient because I wouldn't want it around me. I wouldn't have had experienced it, I wouldn't know what was going on, I wouldn't understand or look at it and analyse what that person was feeling, I wouldn't understand.

(1496)

Masten and Coatsworth (1998) suggest that the experience(s) of trauma and/or adversity can heighten the development of protective behaviours. (I discuss psychological protective factors in greater detail in Theme Two.) These behaviours are related to perceptions of personal safety, self-esteem and self-efficacy. Some participants viewed protective behaviours as an aspect of resilience that enabled them to maintain their psychological safety. For example, one participant stated:

-

<sup>&</sup>lt;sup>19</sup> A role filled by an individual with the lived experience of mental illness who supports others in similar positions.

Protection is vital, especially when it comes to your emotions and your heart.

(1140)

They also stated:

you know, protect myself first. I learnt to keep what's good really close. And I tend to be careful of what's bad and keep it as far away from me as possible.

(1140)

Similarly, participants perceived the ability to detect potential threats, consider situations from different perspectives and act rationally rather than emotionally as integral to resilience:

To be protective of myself, but I wouldn't be quite so objective to a situation. I think that's what my foster family taught me was to look at something in every aspect possibly. (1140)

Conversely, a small number of participants (22%) viewed their resilience as a less stable psychological construct that had been diminished by the enduring, negative effects of CTA. This group of participants struggled to recover from their experience(s) of CTA, with one participant stating: 'I can't get it [CTA] out of my mind. It's like I've lost' (1688). Consequently, this group did not view themselves as psychologically capable or confident:

I haven't got a job, my siblings have got jobs, you know. 'What's going on with me; I'm always sick. How can I do anything?' I felt really low self-esteem and

all that sort of stuff. And with the depression, I lost motivation and I just felt pretty worthless. (1136)

This small cohort appeared to be more psychologically defined by their CTA experience(s) than the more resilient group. They appeared resigned to a more pessimistic view of their future:

The whole time I was growing up and that, [CTA] was in my head there, and then that 'this was my life; it's not going to get any better'. (1117)

I can't be who I am because of what I'm feeling on the inside. (1496)

In summary, there were consistencies across the participant group about the concept of resilience as a psychological asset that enabled individuals to recover from trauma and/or adversity. This view was also evident for the small number of participants who viewed their resilience as diminished in comparison to the majority of the sample. Many participants conceptualised their resilience as representing specific psychological attributes and skills such as confidence, psychological strength, a positive sense of self and the ability to recover from adversity.

Several participants viewed their CTA experience(s) as fundamental to forming and defining their psychologically resilient selves. Their insights into the development of resilience and its characteristics and importance for psychological wellbeing align with the conceptualisation of resilience described in much of the literature. For example, as Johnston-Wilder and Lee (2010) describe, resilience is a combination of personal characteristics and skills that allow people to function despite adversity. Conversely,

resilience can also be perceived as a characteristic that varies with context, time, age, gender, cultural origin and differing life circumstances (Connor & Davidson 2003). These conceptualisations replicate how several participants understood and articulated their own understanding of their resilience. However, although the majority of participants aspired to be psychological resilient, a small number also recounted how their CTA experiences had a permanent and pervasive negative effect on their capacity to become resilient.

## 6.2.3 Psychological Coping and the Reframing of CTA

You've just got to live life I suppose. Not think about it too much. (1930)

Participants reported that they had developed positive psychological coping mechanisms in response to CTA. These mechanisms enabled several participants to 'overcome' (1751) some of the negative psychological effects of CTA including the experience of stigma and social isolation. Moreover, several participants indicated that their coping skills enabled them to manage current life stressors including the many challenges of living with their psychosis.

Psychological coping has been described as an individual's cognitive and behavioural capacity to manage stressful situations and events. More specifically it has been described as the capacity to reduce, minimise, master or tolerate stressful situations. For example, Folkman et al. describes psychological coping as 'a person's cognitive and behavioural efforts to manage (reduce, minimize, master, or tolerate) internal and external demands' (1986, p.572).

Coping emerged as a significant theme from the interview data. As with resilience, coping was predominantly discussed in reference to the ongoing psychological effects of CTA and in the context of illness management. Several participants also demonstrated a well-

developed understanding of the concept of coping and its centrality to resilience. Some also perceived coping as essential to maintaining their emotional equilibrium and their capacity to manage their psychosis and complex life circumstances. For example:

I think that because I had such an experience, it has helped me cope with stress, so like, if I hadn't had that, then I would probably be less able to manage the stress. (1136)

in some ways it's harder to cope. But in other ways I've dealt with it better for having had that experience. (1590)

Additionally, several participants viewed the ability to cope as an outcome of surviving the effects of highly distressing CTA event(s). Some expressed pride in their ability to psychologically cope with and survive their experience(s) of CTA.

It [CTA] doesn't define you as a person, because you experienced the trauma when you were young. I think the ability to cope, once again because I was exposed when I was younger. I think my coping mechanisms are a bit higher than most people. (1791)

Other participants viewed their ability to cope with setbacks and ongoing stressors as being at the core of their resilience:

I think that other people, like my friends and people around who see what's happening, they just can't believe how strong I am, that I can cope with all this.

(1791)

The reframing of the experience(s) of CTA emerged as the most common coping strategy used by participants to diminish the negative effects of CTA on psychological functioning. Participants described reframing as fundamental to maintaining focus and determination:

If you don't have the right attitude, you're not going to last. You're not going to make it. (1686)

Another participant stated:

Convincing myself that everything is OK. Think morally and that sort of stuff. (1930)

Re-framing CTA encompassed a number of strategies. This included shifting from a negative to a positive psychological frame of reference as a way of changing negative thoughts related to the CTA experience(s). For example, one participant stated:

Whenever I'm really down and having suicidal thoughts or majorly depressed or really blue, I start thinking of things I look forward to, things that are going really well in my life, I try and list as many things in my head, I count upon my fingers all the really good things in my life that I really enjoy. (1590)

Replacing negative emotions and thoughts with positive memories was another reframing strategy:

It was like as a kid and what I had to do to not hurt myself. So I live off those times because they were beautiful. (1496)

Several participants had also developed a range of adaptive responses to survive the experience(s) of CTA in adulthood and as a strategy for managing their illness:

Of course sometimes that inner voice is not there and you believe you are crap and you are bad and you're worthless and things like that. I guess when I couldn't fight off those thoughts, those feelings of worthlessness and all of that, but slowly I've come to hear that inner self and say 'hey, you've gone through a rough time at the moment, you don't have to be well straight away and it's okay to feel a bit low from now because it will end and it's not forever'. (1791)

However, some participants also recounted how they had used maladaptive coping strategies to manage the outcomes of CTA in the past. These accounts illustrate that recovery from the psychological challenges created by CTA was a gradual process of acceptance, development of coping skills and the reintegration of the self:

I blanked it [CTA] out for so many years. (1045)

I'm slowly leaning to cope and deal, not so much block it out, but deal with it a bit differently than I did in the past, and not think of it like I did at one stage. As a coping mechanism, I suppose. (1633)

One participant, who was still profoundly affected by their CTA experience(s), concluded that their capacity to psychologically cope with adversity as an adult was permanently diminished:

I don't feel like I do cope. I'm not sure if it's actual coping, because it's like I'm just blank. I'll just blank everything out, and nothing's a problem anymore. I don't think it's coping so much as blanking everything. (1645)

Participant 1645 was one of only three in the Study Two cohort who indicated a less psychologically resilient profile throughout their interview and on completion of the Resilience Scale assessment. A low level of confidence, high anxiety and an inability to cope with conflict was evident during the interview. This participant stated: 'I start yelling a lot, start getting really snappy. Just little things like that that make me irritable (1645) and attributed this to the psychological effect(s) of CTA. They associated this with a lack of trust in others – 'I usually think the worst of a person' (1645) – and perceived it as creating significant social isolation: 'I don't have many friends' (1645). Conversely, another participant who was more moderate in their responses when discussing their experience(s) and the effects of CTA on their psychological selves, stated that 'everything happens for a reason' (1140).

## **6.2.4 Resilience: Conclusion**

I just battle on. That's it really. I just battle on and just give it [CTA] time to just go away. (1469)

In this section I have examined the theme of resilience and the associated sub-themes related to resilience. I asked participants if they considered themselves able to thrive regardless of their CTA experience(s) and ongoing illness. From those discussions CTA emerged as a precursor to the development of positive coping strategies that enabled some participants to reconcile themselves to their CTA experiences and manage ongoing life stressors. As Bonanno (2004) suggests, this ability to thrive in the face of challenging psychological and health circumstances can be a defining trait of an individual who is

resilient. Although there was some variation there was agreement about the construct of resilience across the participant sample, and there was consensus about the role of resilience in surviving past, present and future adversity. Participants identified coping and reframing as crucial dimensions of resilience and essential tools in how they successfully managed their psychosis.

As I have discussed, much has been written about the concept of resilience and the effect of trauma and/or adversity on psychological hardiness (Waysman, Schwarzwald et al. 2001). However, resilience research has primarily focused on adversity such as divorce, illness, bereavement and work stress, events primarily associated with adults and not children. Thus, these topics have rarely been studied in relation to severe trauma and adversity in childhood. The finding that CTA is a possible precursor to the development of resilience in some people is unique to this PhD research. Moreover, I conducted this research with participants who managed a significant mental illness and lived in often complex social and economic circumstances. Despite these factors, the majority of participants (84%) had successfully reconciled themselves to their past CTA experiences. Moreover, they applied and continued to strengthen the coping mechanisms developed in response to CTA as a strategy for managing their psychosis. Furthermore, the majority of participants had a strong sense of self and an optimistic philosophy of life despite their illness and the ongoing challenges of their lives. These findings are congruent with research in the field of trauma that has demonstrated that some individuals experience positive psychological benefits from their struggle with highly challenging life circumstances (e.g. Cox 2004, Calhoun & Tedeschi 2006).

## 6.3 Theme Two: Childhood Trauma and/or Adversity

Because we've been there, we've lived through it [CTA] and known the experience, we know how to deal with it. (1590)

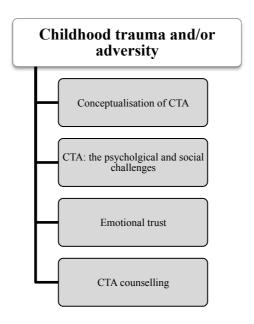


Figure 6.3: Thematic Structure of Theme Two

## 6.3.1 Introduction

This theme further explores participants' personal understandings of the significance of their CTA experience(s). Their accounts create a rich and complex data set from which I have identified consistent patterns regarding the long-term effects of CTA. The primary theme is titled 'Conceptualisation of CTA'. Consequent sub-themes include 'CTA: The Challenges', 'Emotional Trust' and 'CTA Counselling'. These sub-themes are interrelated and they consolidate many of the participants' interpretations of the role of CTA in determining their resilience capacity, as I explored in Theme One.

## **6.3.2** Conceptualisations of CTA

It's [the experience(s) of CTA] hard and I'm still learning. (1496)

As I described in Theme One, a number of participants conceptualised CTA as an event or series of adverse events that led to the development of positive psychological outcomes:

I feel that it's [CTA] helped me to develop skills as an adult that other people don't necessarily have. (1288)

It [CTA] gave me better skills to cope with getting a job, approaching people in a different manner. (1117)

Some participants described how they had developed resilience by reconceptualising and integrating their CTA experience(s) into a positive sense of self. However, although common understandings about CTA and its relationship to resilience emerged, there was also individual variation in the way that participants interpreted CTA and its effects. Almost all participants emphasised that CTA had caused severe psychological suffering. Moreover, a small number of participants within the cohort viewed CTA has having enduring negative effects on their psychological health and life outcomes.

Several participants expressed anger, a sense of injustice and distress when recollecting CTA events: 'it's something that you forget, you don't want to forgive' (1468). Some described their CTA experience(s) as acutely distressing: 'he traumatised me something shocking' (1045) or as particularly frightening: 'I was basically helpless' (1136).

A number of participants remained conflicted about how to reconcile negative psychological responses generated by recollections of CTA. For example, one participant attributed a lack of optimism to their CTA experience(s) that 'made me a lot angrier, less tolerant, less patient, less understanding to other people's views' (1496). Some felt anger towards perpetrators, family members and child or statutory protection services for their perceived failure to act in their best interests:

There was no punishment, family members just pushed it under the rug, and now that I've had a child, that's when it really kicked in as well. (1468)

they [child protective services] just took me away and it frustrated me and made me angry. (1117)

A number of participants attributed their psychosis to their experience(s) of CTA. This is significant given the links between CTA and psychosis established in the literature (Matheson, Shepherd et al. 2013). One participant observed:

I think everybody has their own mental health story, but I believe that it was a lot about the circumstances [CTA] ... that's what bought on my own mental illness and where I am. (1140)

# Another participant stated:

I'm obviously not a doctor, but I have, through going through a lot of the discussions and the psych tests and everything, for the first 2 psychotic events that I've had, it was all put to trauma. So really, I believe that because it [the

CTA] was so specific and so traumatic, whether I was always bi-polar I'm not sure, but I really think it triggered something for me to not have a normal balance of 'this is not right'. Does that make sense? My mind either shuts down, or does whatever it can to cope, and I really think whether it's heightened it, or triggers it, I'm not sure. But I really think it's the basis of my events from then on, till now. (1448)

Some participants also reported that the effects of CTA led to the onset of episodes of depression:

I was empty. I had nothing in life to live for. I didn't want to achieve anything else, I was living every day for the sake of living every day. (1751)

Others considered CTA as the dominant factor within a range of other life experiences and circumstances that contributed to the development of their psychosis:

It [psychosis] is the result of the trauma and stuff that has happened to me in the past that causes the way I act out. (1633)

The negative psychological effect(s) of CTA compounded the demands of living with psychosis for some participants. They identified that recollections of CTA event(s) precipitated the onset of a relapse of their illness:

Sometimes I still cry myself to sleep when I think about what happened to me when I was a child. I try not to do that because that's one of the triggers for me

to become unwell if I start thinking and stewing about what happened to me in my childhood. So I try not to think about it. (1530)

Despite the combined effects of psychosis and CTA on their psychological health, many participants regarded themselves as functioning relatively well. They viewed themselves as psychologically resilient, with the ability to cope with past trauma and also with the demands of living with a complex illness. However, despite these positive perceptions, some participants conceptualised CTA solely in terms of its enduring negative effects on their lives. For example, one participant believed that 'it [CTA] stuck through my whole life' and that 'I can't get it out of my mind. It's like I've lost' (1688). Even those who reported that they had successfully reconciled themselves to CTA expressed regret about lost opportunities and the potential of more fulfilling futures:

I think that if I didn't have any trauma I would have excelled more in different areas, I probably would have travelled; I wouldn't have gotten in trouble with the law. (1645)

## 6.3.3 CTA: The Psychological and Social Challenges

It's always a big stress until I get to where I've got to go. (1645)

As I have illustrated, some participants' recollections of their CTA experience(s) elicited strong negative emotions. A number of participants discussed the psychological effects of CTA on their identities, views of the world and sense of competency at length in their interviews. For example, one participant described how it took many years following their CTA experience(s) to regain a positive sense of self:

It's [self-confidence] still linked back to my trauma. I was starting to be confident and lost it. I got it taken away and it's taken all of these years, over 20 years, to go 'oh, I could actually have a go at that' and no-one is going to belittle me. (1448)

Several described their struggle to 'cope' (1288), and to manage the intrusive and pervasive psychological effects of CTA: 'it [CTA] makes it difficult if it pops into my head, and now I'm grumpy in my day-to-day life' (1486). Some participants attributed their ongoing anxiety and a diminished psychological capacity to managing the emotional stressors related to the experience(s) of CTA. One participant described how their inability to manage stress precipitated severe psychological responses. One participant stated: 'I stress out. I start screaming, ranting, and raving and use drugs to mask the pain' (1233). Other participants also reported that they used drugs to manage anxiety and stress, with one stating: 'I did do drugs, I did do alcohol' (1385).

Some participants stated that anxiety compromised their ability to cope with the negative outcomes of CTA. This was particularly evident for some participants when intrusive psychological or social triggers and/or cues precipitated recollections of CTA events. Participants stated:

I used to shake like a leaf when I came near my street from school thinking 'oh god, what's today going to be like'. (1608)

every time I think of this man I get anxiety and I feel threatened. (1686)

Two participants described anxiety that was so severe that it compromised day-to-day functioning: 'I want to cry a lot, and I'm fearful in my own home' (1385), and 'sometimes the anxiety can cause the panic' (1686). Some CTA experience(s), particularly those of a sexual nature, raised feelings of shame, loss of confidence and regret about losing the opportunity to experience life in more psychologically fulfilling ways:

I felt really low, self-esteem and all that sort of stuff. And with the depression, I lost motivation and I just felt pretty worthless. (1136)

Some participants identified a connection between guilt, loss of confidence, and the consequent emotional and social isolation: 'I don't talk to anyone else, not even my sister or my brother about it [the experience(s) of CTA]' (1225).

Other participants associated CTA with poor self-esteem that created psychological barriers to establishing positive relationships:

I did sleep around because, like I said, if a man has sex with you I thought that was love. I don't understand the difference between love and sex. (1385)

my lack of confidence, feeling of being unworthy, of being loved. I choose below myself all the time. (1688)

A number of participants expressed regrets about their social isolation, and lack of supportive social networks and stable family relationships: 'I've never been married, I've never had children, and I find that really sad' (1385). Some also believed that CTA

negatively influenced the development of important social competencies during childhood and adolescence essential for forming positive relationships:

My childhood trauma has affected my ability to be able to be intimate with another person. I had a lot of trouble in my marriage with intimacy. That's one of the reasons my marriage broke up. My husband couldn't handle it. (1530)

it actually took away my abilities [to develop positive relationships] on my brain. (1136)

Participants identified that their inability to communicate, negotiate and manage conflict hindered the development of mutually supportive and respectful relationships:

It [CTA] affects my relationships with women because I tend to be violent, because that's all I know about how to handle a situation with a woman. (1469)

In addition to negative thoughts and perceptions about themselves, some participants viewed CTA as inhibiting their cognitive development. These effects included difficulties with 'concentration, memory, withdrawal symptoms' (1686), as well as confusion when confronted with psychologically stressful events: 'I get confused at the same time because it just brings back the past' (1468). When discussing learning and development during their formative years of childhood and adolescence, some other participants noted that CTA had severely affected both their cognitive and social development:

I did develop very differently. I think my learning difficulties that I experienced from grade three to five were directly due to the psychological damage I had

[from CTA]. Not only was it due to the psychological damage, I wasn't able to learn interaction skills, how to learn. It had an impact on my learning, on my attitude towards people. I guess I really hated people. (1546)

Some identified long-term cognitive effects that limited their consequent educational and vocational opportunities:

It [CTA] affected my life at school. Learning was very, very hard for me. I could learn something, and a short period of time later I had to learn it again. I forget some things. Even to this day I find things hard to remember at times. (1686)

Some participants described how the effects of CTA restricted their employment opportunities: 'I've found it hard to hold down a job' (1385). This impacted on their economic security:

I got bullied at work and, I got bullied for about 2 years, went in there every day, got bullied, came home and the next day I'm thinking 'oh, what's going to happen today again?' (1608)

I'm finding it reasonably challenging to stay in employment, jumping from job to job, having days off and other factors that arise in my life. (1751)

As I have described, some participants expressed a range of negative emotions such as anger, anxiety and regret when recollecting their CTA experiences and their psychological effects. They portrayed the adverse effects of CTA as ranging from anxiety to cognitive

impairment, loss of trust, and social behaviours that led to interpersonal conflict. For some, these effects created difficulties maintaining intimate relationships, social connections and employment. Consequently, these participants conceptualised CTA solely in terms of its negative long-term psychological consequences on their health and life outcomes. These views are in contrast to the majority of participants who had a more enabling view of CTA, which included the positive psychological outcomes that were achieved as a result of their struggle with CTA. As I will explore in Theme Four, the latter group were clear that they would not choose to change their life trajectories including their experience of CTA.

#### **6.3.4 Emotional Trust**

I didn't trust anyone around me. (1288)

The construct of emotional trust has long been acknowledged in the literature as a psychological 'event' or a 'multidimensional social reality' (Lewis & Weigert, 1985). Baier conceptualises trust as 'accepted vulnerability to another's possible but not expected ill will (or lack of good will) toward one' (1986). The concept of emotional trust that I use in this PhD research draws on the participants' own accounts and understandings of the importance of emotional trust in their lives. I examine the participants' views about their ability to develop emotional trust following their CTA experience(s) (Blomqvist, 1997). I frame their interpretations of the construct of emotional trust within the psychosocial domains of friendship, relationships and their assessments of their ability to engage with their social and economic worlds.

Research in the field has established that a loss of emotional trust in the safety and predictability of the world is a common psychological effect of the experience of trauma

and/or adversity (Gobin & Freyd 2013, Guasto 2014). Several participants' interpretations of their responses to CTA confirmed these findings:

I just can't trust anyone. I've been let down before with a couple of girlfriends and now I just don't want to trust. (1385)

I'm scared of getting hurt. I'm scared of mixing with people or getting too close. (1608)

Participants provided insightful accounts describing how lack of emotional trust diminished their capacity to develop and sustain positive relationships. One participant observed:

It takes me a long time to trust someone or trust something. I've got lots of people in my life but only a few people I trust. (1530)

Participants associated low levels of trust with emotional vulnerability, poor self-esteem and a lack of intimacy:

For every boyfriend I've had; I've only had two that I've lived with, and I couldn't trust. I thought that sex was love and when they didn't give me sex then they didn't love me. Or if I thought they were talking to another woman then they're sleeping with them and I drove them away from me. (1385)

Participants also attributed self-defeating behaviours that led to poor relationships to a lack of emotional trust:

If I don't care that much for you and I feel that you are betraying me very early on in our relationship, then, no. I will just be done with it. It's just not worth it. (1140)

I've developed an attitude, I guess, towards men. It did affect my ability to have a relationship and I have dealt with some of those issues that did have a marked effect on me. (1546)

Furthermore, there was strong evidence that a lack of emotional trust led to the development of protective psychological behaviours that defined some participants' conduct within their social and intimate relationships. For example, a participant reflected:

I'm a very forgiving, optimistic human being. But I tend to destroy a friendship or a relationship if I feel that I have been betrayed, or that the people that I have been honest with, umm, I use the term to nip it in the bud quickly, but I definitely act on emotion rather than thought. (1140)

Another participant reported that a lack of emotional trust required constant vigilance based on the need to minimise potential harm to themselves and their families. They stated:

I have skills as an adult that other people don't necessarily have. I'm not as trusting, I pick up warning signs about people sometimes, and I say, 'I don't trust that person'. (1288)

Another said:

if I don't trust in what you are doing, or trust in what may result in what you are doing, then I don't want a part of it. (1140)

For another participant, lack of emotional trust extended beyond social contacts to include authority figures and institutions:

I think it made me think that I didn't like authority ... I didn't like being told what to do. I think I was always scared of what was going to happen when the authority was put down on me. (1117)

Several participants attributed their diminished emotional trust to their CTA experience(s). They perceived that their lack of emotional trust had a negative, far-reaching impact on their emotional and social wellbeing. As one explained, the experience(s) of CTA had affected their feelings of safety and security around others. This consequently made them reluctant to open themselves up to others for fear of exposing their vulnerabilities:

I don't think you can whole-heartedly give yourself to somebody if you are not whole and complete yourself. And I am certainly not whole and complete myself, far from it. (1140)

## 6.3.5 CTA Counselling

I couldn't get in anyway [to counselling]. So I coped as best I could. (1448)

Prior to commencement of the interviews I anticipated that some participants within the cohort might have accessed counselling for CTA. Had this occurred, it might have

influenced some participants' conceptualisations of CTA and assessments of their own resilience. In particular, counselling might have directly supported participants' development of the coping strategies that enabled them to reconcile and recover from their CTA experiences. As I have described, psychological coping was integral to many participants' self-efficacy and their concepts of a resilient self. Therefore, I considered it important to explore participants' insights about the influence of counselling on their coping skills and associated resilience.

I asked all participants if they had engaged in any type of CTA-specific counselling and, if so, to assess its effectiveness. Across the cohort, only three had received ongoing counselling for CTA, while the remainder had limited or no engagement with counselling for CTA. A participant who had not received any CTA counselling observed:

If I could have turned it around, if someone had helped with the trauma, I would have had earlier skills [to psychologically cope]. (1448)

Participants provided several reasons for their lack of counselling for CTA. This included a lack of awareness of counselling options and/or limited information about the availability of services:

I didn't know there was [sic] people out there. I didn't know where to go to seek help. I just thought it was just normal just to be. (1751)

Poor access to counselling services was also cited:

I tried to get in but everywhere was shut, or not shut, but I couldn't get in anyway. So I coped as best I could with friends, going to people's houses and getting counselling. (1448)

Others were more ambivalent about the benefits of counselling:

I started counselling at 13 at [service name deleted]. I had to go again for anger management at 14. I did some family counselling at sixteen. I did two sessions and then I didn't bother. (1496)

One participant recounted that CTA was not addressed during a mental health consultation because 'the psychiatrists didn't believe me' (1590). Some were reluctant to pursue counselling for CTA as they wanted to avoid addressing a distressing past event(s): 'I didn't want to re-live what happened to me' (1530), and that:

I think sometimes it is better to leave it where it is. I can't do much about it at this time. (1686)

A participant 'didn't bother' (1530) to pursue counselling as they were attempting to manage other challenging health priorities. Some also expressed ambivalence about the value of future counselling for CTA, with one considering it a probable 'waste of time' (1645) as they had come to terms with their CTA experience(s).

The reasons for the comparatively low levels of engagement in counselling for CTA in the participant group are difficult to determine. As I have stated, some participants identified limited access to information and services. This could be attributed to the low level of economic capacity and the restricted resources of the community in which participants lived. Furthermore, as I previously stated, the cohort viewed psychosis as the predominant life issue – 'it has a major impact' (1140) – that defined the health and social focus of their lives. Managing their illness depleted some participants' emotional resources and therefore had priority over addressing past CTA experience(s). Moreover, the management of psychosis symptomology and illness recovery are the primary objectives of clinical and health services. Consequently, psychological symptoms not directly related to psychosis may have remained under-addressed, placed in the domain of mental illness case management, or perceived as the responsibility of the individual.

It is possible that the low level of clinical acknowledgement of CTA in this cohort overlooked some of the coping strategies participants had developed through successfully managing the psychological challenge of CTA. These competencies were evident across a large portion (76%) of the cohort. They provide evidence of participants' capacity to adapt psychologically to adversity and stress. Identifying and further developing these skills through counselling would seem to provide an opportunity to address the major health and social challenges of participants' lives. Moreover, two participants within the cohort believed that they had sustained permanent 'damage' (1546) from CTA, particularly when some of the related psychological effects did not abate in adulthood. Hence, interventions for CTA may have accelerated some participants' psychological recovery from the adverse effects of these event(s). Intervention for CTA may have also ameliorated its long-term effects such as missed educational opportunities identified by participants. Moreover,

given the links between psychosis and CTA, it is possible that early intervention may have acted as a mitigating factor in the development of psychosis.

#### 6.3.6 CTA: Conclusion

We all have bad incidences [referring to CTA]. (1486)

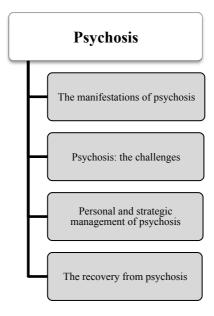
As evidenced in the thematic analysis of the interview data, the majority of participants viewed themselves as psychologically resilient and functioning relatively well. This is despite CTA and the ongoing health, psychological and social difficulties of living with a psychotic illness. This group of participants appeared to have psychologically constructed the effect of CTA as enhancing their emotional strengths and abilities to manage complex challenges. However, a small number of participants also interpreted the psychological and social outcomes CTA as being profoundly negative. They viewed CTA as compounding the emotional and social difficulties created by their psychosis. This group attributed their ongoing anxiety, lack of interpersonal skills and cognitive difficulties to the enduring legacy of CTA. Regardless of the perceived outcomes of CTA, almost all the participants expressed strong negative emotions such as anger, regret and grief about lost opportunities when recollecting CTA events and their effects.

In regards to the interrelationship between CTA and psychosis, it is important to consider that the experience(s) of psychosis can in itself be psychologically traumatic. The symptomology of the illness can create significant emotional and socioeconomic stressors that can severely disrupt the patterns of individuals' lives. It was evident that the personal management of psychosis required significant emotional and physical fortitude. Almost all the cohort was focused on managing their psychosis and perceived CTA as of lesser importance in maintaining good psychological health and wellbeing. Moreover, emotional states such as anxiety and depression, which they attributed to CTA, may have been exacerbated by participants' psychosis symptomology. Nevertheless, participants within the cohort attributed their resilience to coming to terms with CTA and its emotional,

physical and social consequences. They conceptualised CTA as a process through which they had developed the psychological competencies that enabled them to cope with, and recover from, psychosis.

# 6.4 Theme Three: Psychosis

Psychosis is a very scary experience because you tend to push people away that you need the most. (1496)



**Figure 6.4: Thematic Structure of Theme Three** 

# 6.4.1 Introduction

Theme Three examines participants' perspectives about living with psychosis. It includes four sub-themes based on participants' descriptions of the frequently severe effects of psychosis on their health, and psychosocial and vocational functioning. These accounts provide an insight into the personal reality of living with psychosis and the challenges of managing its symptomology. All SHIP participants had been diagnosed with psychosis for some years. Many viewed the illness as a lifelong condition. As I have stated, managing their illness was a priority in their lives. In view of this, I explore the strategies that participants applied to maintain their health and functioning in a separate sub-theme.

# 6.4.2 The Manifestation of Psychosis

If you're psychotic, you don't know you're psychotic. (1590)

The majority of participants identified psychosis as the dominant challenge in their lives. Although some struggled to lead fulfilling lives – 'it [psychosis] can be very hard at times' (1686) – they appeared resourceful, determined and hopeful about their future. Long experiences of living with the illness had brought acceptance of its often-disabling health and social consequences for the majority: 'it [psychosis] not only affects day to day, it affects you physically as well' (1496). Most had developed the psychosocial resources to manage their psychosis successfully and were confident about their ability to sustain their illness recovery. Some reported that they were either 'progressing' (1468) in successfully regaining their health or they viewed themselves as physically and psychologically 'well' (1400). Additionally, the entire interview cohort was living independently in the community and some appeared to thrive on their independence. As one participant described:

I thrive on the responsibility. Paying the bills. I love to do it now. Before I didn't care about it. But now I love to have my house in order. (1117)

As I have stated, some participants expressed optimism about their ongoing recovery and futures:

*I can see the betterness of things happening.* (1117)

it's [psychosis] okay, actually. I know the triggers and the warning signs, and I either medicate myself with PRN medication, <sup>20</sup> or I go out and put myself around people. (1751)

Participants who expressed confidence in their ability to maintain their illness recovery indicated that they had become increasingly able to engage with social and community networks. This linked them to others, reduced their social exclusion and created more enabling personal environments. This in turn helped sustain their illness recovery:

I've taken the path that was getting me out of control, I've taken that out of my life and I've dealt with the things I've needed to deal with by taking them out of my life and it was like a new world for me. (1117)

Others attributed this renewed confidence to the resilience they developed through managing the distress created by their experience(s) of CTA. Some attributed their self-confidence to both CTA and their ability to manage their illness:

He [the psychologist/counsellor] just said, 'go there and stick with the situation and don't pull out of the situation. Don't leave, just ride it through'. It's difficult sometimes, yeah. I'm confident. (1930)

In the context of psychosis and CTA, several participants' views of their illness were shaped by how effectively they managed its symptomology: 'I'm better with it [psychosis illness symptomology] now. I know my warning signs and when I'm becoming unwell' (1839). A number also felt that they understood and had some control over their illness:

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<sup>&</sup>lt;sup>20</sup> PRN: medication taken as needed.

So I'm always managing how I am and learning over the years that I have a better control over it [psychosis]. But I'm always very wary of situations that can trigger me. (1448)

Some participants noted that they had accepted the limitations psychosis imposed on their lives and described their self-care and self-help management skills:

The strategies of going out to visit friends ... it sort of relaxes my mind; it takes my mind off of my mental illness or anything to do with it. It sort of degreases it from getting bad. (1469)

Participants' level of resilience is evidenced above, not only by their determination to remain well, but also in their confidence in their abilities to identify triggers and manage the impact of psychosis on their health and wellbeing.

# **6.4.3 Psychosis: The Challenges**

I thought 'oh my god, I brought shame on my family again, the embarrassment of having a daughter in and out of a mental hospital' and things like that.

(1791)

Despite positive interpretations of living with psychosis, participants also described how the experience(s) of CTA, combined with the challenges of managing this complex illness, presented significant health, psychological and socioeconomic challenges. Although all participants were receiving treatment for psychosis, not all were confident about their ability to manage their illness successfully:

I'm erratic, and sometimes I do hear a bit, and sometimes I don't. So there are quiet times and there are frequent times where I put my defences up and it's just more frustrating and I could kick myself. (1751)

This small group of participants focused on the ongoing challenges involved in combating their illness:

I get very depressed. I get schizophrenic symptoms; I get imaginary voices telling me what to do and I don't hear voices like you and me talking and I can hear you. I get things in my head, telling me the negative parts about me and I twitch my face and I do what everybody else does; you know, I talk to myself. (1742)

A participant from this group reported that their ability to function in daily life was often compromised:

It [psychosis] stops you from just doing day-to-day things. Sometimes you get to the stage where, when you are in a psychosis, where I won't eat or drink or I'll sit there with my muscles tense and I'll have hypertension because of my state of mind. (1496)

Another provided a similar account of the distressing personal reality of living with a psychotic illness:

There's been many a time when I have contemplated suicide. There's been many a time when I have attempted suicide. I'm not proud of it and I wouldn't do it

now, there's other options than that. But when I get unwell that's what I try to do to myself, to punish myself. (1530)

Moreover, participants identified psychosis as an impediment to employment: 'I was very unemployed and my illness was like a full-time job' (1136). Limited opportunities for employment and economic participation created intermittent financial stress and difficulties in areas such as housing for some participants.

Literature in the field has established that mental illness, particularly psychosis, can create stigma and discrimination (Corrigan, Thompson et al. 2003, Adhikari 2007). This can be attributed to how the illness can be manifest in public (e.g. hearing voices, challenging public behaviours) as well as deeply entrenched societal attitudes. This was evident in the experiences of some of the Study Two participant cohort. For example, a number of participants identified stigma as creating feelings of separateness: 'living with it [psychosis] is pretty difficult because other people don't understand you' (1136). Stigma was also an impediment to how some participants engaged with their families: 'people judge you before they understand you and like, my son still doesn't understand' (1225). It also impacted on participants' social roles and their confidence in their ability to engage with the community:

Going places and just getting used to it. I went to the Showdown [and Australian football league match] on Saturday night and it went all right. I've done it previously and once you've done it a few times it's easy. It was the psychologist who helped there. He just said: 'go there and stick with the situation and don't pull out of the situation. Don't leave, just ride it through'. (1930)

Stigma also influenced how a participant perceived their illness and engaged with treatment services:

Even though I have schizophrenia, I feel offended going to [name of service provider withheld], not because I feel that I am better than some of these people with illnesses, it just makes me feel, I'm looking at them and they're looking at me in the sense that I was once like that. Sitting there like this [demonstrates continuous rubbing of knees] all day. I was like that for years and years and I don't want to be reminded of that. I'm not sick like I used to be, I'm not as bad as that. And when I see that it reminds me of all those years I was in the hospital doing exactly the same thing they're doing and getting nowhere. (1686)

The above sub-theme confirms that psychosis had a negative impact on many aspects of participants' health and wellbeing. For some participants, psychosis created psychological disintegration, disruption and disconnection from which they were struggling to recover.

### 6.4.4 Personal and Strategic Illness Management of Psychosis

I've moulded myself on the circumstances that I've gone through. (1686)

Several participants discussed strategic illness management as essential to ensuring that their recovery was sustainable. As I have stated, the ongoing demands of illness management took precedence over any desire to resolve the enduring effects of their CTA experience(s). Some participants viewed the combined challenges of living with psychosis and the emotional difficulties arising from the experience(s) of CTA with some

pragmatism. They conceptualised their psychosis as a problem that could be strategically managed by being determined and focused. Moreover, they demonstrated a strong desire to remain resolute despite these ongoing obstacles: 'just going forward instead of going backward' (1045), or 'just look at a problem, approach it and deal with it' (1117). Furthermore, the reframing of negative emotions and thought patterns was a dominant illness management strategy cited by some participants:

For me I always work on my mind and how I can help with the thoughts. So for me, I know I have a fear and I know I can bring in that fear very easily, especially in a high stress job. And being a single mum, I really worked on my thoughts and my emotions. I do a lot of things that help me balance a lot more. (1448)

The process of reframing can be described as the identification of negative thought patterns, appreciating positive moments and developing positive perspectives about individual capabilities. This description is similar to how participants reframed their responses to recollections of their CTA experiences. One described this process:

I've always been a happy person, so I used to look at work and think 'oh we've three more days to go', and the things that would get me through those three days was the things ahead. Whether it was just a family barbeque, or relaxing having a DVD night or take out, or anything small that you are looking forward to, that's what helps. (1468)

Another similarly described identifying and controlling negative thoughts, feelings and behaviours through positive self-talk as an effective coping strategy:

I just take deep breaths when it gets to me and just talk to myself sometimes. When I talk to myself I try to give myself incentives to stay positive and saying 'keep achieving, keep achieving' and if it does get too bad I just go to the doctor. (1751)

For other participants their coping strategies involved engagement in physical activity:

I go for a walk, 'cos walking actually lifts your mood. I've been feeling a lot better since I have been walking the girls to school now. When I am out of the house, and if I find if I am doing creative stuff, then I'm a lot happier if I do that sort of stuff. (1288)

Some participants said that maintaining daily structure and routine was important:

With no structure to my daily routines, too much time on my hands, I get up to mischief. (1233)

I just keep myself busy. So long as I keep busy and I keep my mind active on the good things and something I enjoy, it balances it out. (1496)

The need to build and maintain enduring social relationships was also an important consideration for some participants:

A really stable environment, home environment, which has always been very important to me. I can work in the world and achieve a lot I wasn't sure I was

going to achieve. I've kept some really strong, and made some really strong relationships, which goes back to the childhood moving a lot. And I wasn't sure that I could do that. (1448)

Proactive strategies included maintaining and accessing both formal and informal support networks:

Goals, people to talk to. Just going out and enjoying myself when things get too bad. Talking to my brother, or talking to a psychiatrist or a psychologist and getting some and set some boundaries to what I can do to implement in my life where I can get some structure to it. (1751)

Finally, some participants cited remaining intellectually connected and engaged as important to leading a meaningful life:

I just read. I go with my hobbies, I read up on politics, or I'll read up on computer information over the Internet. I use social networking as a coping mechanism, socialising over the Internet. Just reading and becoming smart, and learn more about business and accounting, and more about administration. I've got set things where I sit on the computer and read all day or read for the whole week, sort of thing. I watch movies and various other things. (1751)

In summary, a number of participants described a combination of positive psychological and practical coping strategies they applied to manage their psychosis. These ranged from psychological reframing to maintaining daily routines and structures. As I have stated, they also applied some of these strategies, such as reframing, to manage the effects of CTA.

Participants attributed their ability to manage the health, psychological and social challenges of psychosis to either their experience of surviving the experience(s) of CTA or to a combination of learning to cope with both CTA and their psychosis. The ability to draw on the psychological strengths developed from their CTA experience(s) to cope with the additional health and psychosocial adversity of psychosis demonstrates participants' psychological adaptability and resilience.

## **6.4.5 Recovery from Psychosis**

My illness was like a full time job. (1136)

Recovery from psychosis is the fourth and final sub-theme to emerge from my analysis of the interview data. I describe participants' insights into their illness recovery. The concept of recovery was well understood across the cohort and participants applied it to describe the outcomes of their 'health' (1136). As I have stated, sustaining their illness recovery was a priority in the lives of participants. Some viewed psychosis and recovery as inextricably linked, while others defined their illness in terms of being unwell, becoming well and then recovering. However, the notion of recovery was not addressed directly in the interviews. It emerged when participants were responding to questions about their experience of psychosis and how they personally managed their illness. Given that the current discourse within mental health practice and clinical service delivery emphasises the importance of engaging mental health service users in their own 'recovery', it is not surprising that participants raised this topic in the context of their illness.

Acceptance and reconciliation appeared to be integral to how participants viewed their successful recovery from psychosis. As I have stated, the majority of accounts confirmed that participants were reconciled to the fact that they lived with a lifelong mental illness that had a severe impact upon their health, and psychological and social functioning. They

described the course of recovery as occurring over time: 'it's [psychosis] been difficult initially. Initially it was hard to accept what I, that I had an illness' (1791). As I have outlined, a long history of managing their psychosis had enabled a number of participants to develop the psychological resources to manage their illness symptomology and helped ensure their recovery was sustainable. Those who expressed confidence in their illness recovery also demonstrated optimism about their futures. For example one participant stated:

I feel that as the years go by it seems to be longer and longer between whenever I've had a relapse. (1633)

Participants in the cohort had engaged with a range of mental health services and treatment programs. Some referred to the development of clinical management plans as a familiar step in their treatment experiences. These clinical plans have commonly been utilised across South Australian health services, including in inpatient and community mental health services, GPs, primary care and in non-government mental health settings. They are designed to engage service users in their own recovery process to achieve self-directed health outcomes. Some participants identified mental health services as crucial in sustaining their recovery:

With the support of the mental health services [I cope] really well, really, really well. All things considered. And then there are times when I don't cope so well and I may need an emergency psychiatrist appointment, or go into [inaudible]. I try and make an emergency counselling appointment with [deleted] at the time they are open. I think one of the worst times when I was psychotic, and I knew I was, Dr [name deleted]; my psychiatrist, told me 'if you're psychotic, you don't

know you're psychotic'. But I knew something was really wrong because I couldn't even go into my local shops without hiding behind the fruit and veg. After I had bad chest pains from the food poisoning, which led to relapse in mental illness, with paranoid delusional psychosis. (1590)

Another participant expressed similar positive feelings about their involvement in mental health services:

They've always been a part of my life, but I didn't know how much I needed them to exist. I'm very anti-drugs and in my, the first time I had a big psychotic event, I'd actually had drugs, cannabis, so that proved to me I can't do it. But the other thing is to be in touch with psychiatrist and a lot of people in the medical profession that don't all necessarily agree with the drugs, and I was very much aware of being drugged to the point where I couldn't function properly and not allowing myself to re-generate and actually manage it, because I think I'm a highly intelligent person and I think I had a psychotic event. But my body and my mind quickly can get back on track. So having the drugs then gave me huge side effects that I found really debilitating. (1448)

This participant identified that having confidence in mental health services was a precursor to engaging in treatment:

Because I've had such traumatic experiences with the mental health, I actually have a fear that I was mistreated and mishandled and misrepresented and therefore I don't listen to people who are actually trying to help me. So now,

because I've had a more positive experience, I'm willing to listen to people and say; 'look, I'm feeling a bit wobbly'. (1448)

A number of participants indicated that the most important aspect of managing their recovery was learning about the course of their illness and how they could manage its symptoms. They saw this as crucial in helping them to identify the risk factors that may have contributed to their psychosis, learn management skills, and take personal control of their recovery:

I was continually hearing things but I couldn't accept it as a person. But once I accepted and understand it and seeked [sic] additional information and help I had a more understanding of the triggers and the various aspects of how it could be implemented on someone's life. (1751)

Several participants perceived that illness medication was fundamental to maintaining their ongoing psychological wellness. However, they also identified that understanding the purpose of medication and its potential side effects was integral to self-management:

If I understand what's going on [with medication], then I can control it [the illness symptomology] a bit more. (1496)

Another participant stated that the value of medication was significant for their illness recovery:

the new drug I'm on, Lithium. Fantastic! I haven't been in hospital since August last year. (1530)

Other participants stated that the effectiveness of medication was increased by the application of the self-management strategies that they had learnt over time.

Given that participants had lived with psychosis for a number of years, they viewed illness recovery as a continuing process that enabled them to engage confidently in their social and, to a lesser extent, economic lives. When discussing their recovery they described their experiences with a range of services, treatments and programs. They described effective mental health treatment as providing ongoing individual support focused on understanding their illness, identifying life stressors and early warning signs, and helping with day-to-day and long-term management:

Every time I go to the hospital I talk about my experiences there and they talk to me and give me some feedback and ask questions. (1751)

### **6.4.6 Psychosis: Conclusion**

*The fear is immense.* (1448)

This exploration of participants' diverse experiences, understandings and interpretations of their psychosis and recovery highlights the enduring effects of the illness on their ability to function psychosocially. A consistent theme across the cohort was that managing psychosis requires endurance, tenacity, and extensive health and social support. Numerous participants identified a range of individual strategies they had learnt to manage their illness symptomology. One group of participants viewed themselves as coping successfully with their illness and were optimistic about maintaining their recovery. They had accepted that they had a lifelong illness and were determined to manage its often-disabling effects. Another group of participants indicated that psychosis had significant negative long-term effects that presented them with daily obstacles and challenges. In analysing the ways that individuals managed their illness, I found that many applied similar strategies to those they used to cope with the effects of CTA.

### 6.5 Theme Four: Reconciliation, Post-Traumatic Growth and Speculative Change

Everybody says: 'get on with your life', and that's what I'm doing, getting on with my life. (1688)

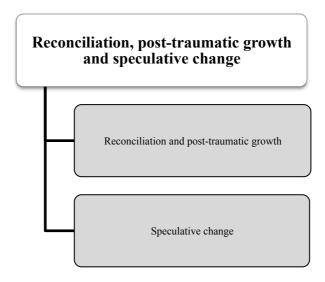


Figure 6.5: Thematic Structure of Theme Four

### 6.5.1 Introduction

As I have discussed, numerous participants discussed how they had reconciled themselves to the emotional and psychological challenges of their CTA experience(s). In addition, post-traumatic growth (PTG) following CTA emerged as a significant theme from analysis of the interview data. The sub-theme of 'Reconciliation and Post-traumatic Growth' emerged from these discussions. This sub-theme encapsulates how individuals psychologically reconciled the negative effects of their CTA experiences to develop inner strengths that enhanced their social and emotional wellbeing.

In addition to investigating the notion of CTA reconciliation, I also explored the concept of alternate personal realities with participants during the interviews. This sub-theme is titled 'Speculative Change'. It includes a number of participant reflections about how they imagined their lives would be without the challenge of psychosis or CTA. The intention of

this question was to provide participants with scope to consider possibilities beyond their current life experiences. Participants were highly engaged in this introspective component of the interview, often taking time to contemplate alternative lives and futures. Their accounts substantiate the findings from previous themes regarding the significance of CTA and psychosis in defining their life trajectories.

### 6.5.2 Reconciliation and Post-Traumatic Growth

*It's the attitude to bounce back.* (1686)

Reconciliation has been defined as a process that occurs when a person works to integrate a new reality of 'moving forward in life' despite the experience of trauma and/or adversity (Cohen, Mannarino et al. 2002). Given this, one participant interpreted their experience of reconciling themselves to CTA as a process that had led to long-term psychological benefits:

It [CTA] is like metal, or diamonds, or gold; you can't get gold unless you refine it. If you don't refine it, then it's just useless to you. (1686)

Reconciliation after CTA was evident from individual accounts. These accounts described how participants adapted to, and grew from, their experience(s) of CTA to consequently apply their skills to cope with future adversity. The majority of participants within the cohort accepted that little could now be done to change the occurrence of past CTA event(s): 'you can't really take back what's done' (1496). Despite living with complex psychological and social challenges, many expressed a sense of achievement in their ability to adapt positively to their life circumstances:

After that kind of shit [CTA], I went straight into a domestic violence relationship for 2 years of my life, and then another domestic violence one. Considering the extent of everything I've been through, I think I'm doing fucking excellent. I think I'm doing fucking excellent. I'm lucky to be half the person I am. (1496)

A consistent finding across the cohort was that participants highly valued the positive psychological benefits that they had gained from coping with highly adverse CTA experiences. One participant stated that 'I wouldn't change anything' (1288) despite the psychological and physical trauma of their experience. However, as I have previously stated, participants emphasised that the process of psychologically reconciling CTA experience(s) to achieve positive outcomes was protracted and emotionally difficult, particularly when their CTA experiences had been violent:

Growing up with so much violence, it's like you've got to train yourself to be different to what you already know. (1496)

Individual accounts of positive coping and personal psychological growth do not mean that CTA experience(s) did not leave deep psychological scars. The process of psychological adaptation involved in recovery from CTA continued to be deeply challenging for some participants. For example, one participant stated:

I don't know how many times I'm going to have to deal with it [CTA] in my life.

(1496)

Nevertheless, several participants also described the positive capabilities and dispositions developed as a result of their psychological struggle with the experience(s) of CTA. They highly valued their resilience and, as I have discussed, identified reframing as the dominant coping strategy they used to adapt to past CTA experience(s) and current life stressors. In some instances, their description of the positive psychological changes they had experienced provided evidence of PTG. As I have illustrated, the majority of participants believed that they had developed a stronger sense of personal strength, enhanced emotional and social capabilities, clear life priorities, and a determination to focus on future possibilities. For example, one participant stated:

I wouldn't change the experience of the trauma because I wouldn't be who I am. (1496)

However, a number of health, psychological and social variables may mediate the relationship between CTA, resilience and PTG. It is possible that some participants' high levels of PTG may have positively influenced their interpretations of their past CTA experiences. Moreover, as literature in the field indicates, the characteristics of a resilient person include optimism, self-improvement, coping and a sense of coherence (Tedeschi & Calhoun, 2004). This cluster of personality traits allows individuals to continue psychosocially functioning despite the experience(s) of trauma and/or adversity. These traits may have provided participants with the psychological capacity to rebound from stressful events. The following participant, who perceived their resilience as a lifelong psychological attribute, supported this view:

'I've always been resilient. I've coped with a lot of things in my life; it's what I do and what I am. (1400)

Acceptance and reframing of CTA allowed some participants to make sense of the experience(s) of their trauma and/or adversity and to integrate these into a strong sense of self. For example, a participant stated: 'it started me off on this journey of becoming who I am' (1140). Some also expressed a strong belief that CTA had strengthened their internal capacity to confront and mange life challenges: 'I think I can cope with a lot more stress, a lot more problems' (1117), and: 'it [CTA] made me stronger [psychologically]' (1791). Participants described these competencies as the ability to solve problems, negotiate with others and manage their illness:

If I could take the trauma away then I wouldn't have learnt the coping mechanisms to cope with trauma. (1751)

Another participant observed that individuals require adversity in order to learn personal strengths and coping skills. One participant provided an account of psychological growth following CTA, which encapsulates the concept of PTG from literature in the field:

I'm a better person for it [the experience(s) of CTA]. I would prefer not to have gone through it because it's not pleasant. But on the other hand, I don't think I would change my life, because life is a learning process and I believe people go through trauma, any kind of trauma, whether it be childhood abuse or diagnosed with a terminal illness or mental illness. I think we go through all of those things, the bad things in life, so we can help other people coming through it. (1590)

As I have stated, an important part of the reconciliation process was the view that the experience(s) of CTA enhanced an individual's psychological strengths:

It [CTA] doesn't define you as a person, because you've experienced the trauma when you were young. I think the ability to cope, once again because I was exposed when I was younger; I think my coping mechanisms are a bit higher than some people. (1791)

Important to the concept of psychological strength was the belief that CTA had enhanced a person's emotional capabilities:

I learnt something from it [CTA]. I learnt compassion, I learnt patience, I learnt tolerance. Because I know what it's like. (1686)

This included the ability to care for others:

It's [the experience(s) of CTA] made me more compassionate, more empathic, even more sympathetic. I think it [the experience(s) of CTA] has made me more resilient in terms of giving me good communication skills. (1590)

As I have previously described, being psychologically resilient was integral to a number of participants' belief in their own self-efficacy:

I suppose if I hadn't had too much trauma I would be less resilient. I really do.

I would be less resilient because I wouldn't want it around me. I wouldn't have had experienced it, I wouldn't know what was going on, I would understand or

look at it and analyse what that person was feeling, I wouldn't understand. (1496)

Some other participants reported that a positive outcome of psychologically coping with CTA was that they focused on the future:

I've learnt from my mistakes and I'm moving on and not dwelling on the past. (1751)

Another psychological benefit participants noted was the emergence of a strong personal identity and optimism about the future:

It [CTA] happened in the past and has made me the person I am today and I am constantly improving, trying to improve myself, and trying new things out and see if it makes me happy. (1751)

I always go forward, for my children. Before I had them, I kept on going backwards. (1045)

The majority of participants stated that they were reconciled to experience(s) of CTA. This may be a reflection of adversarial growth (Linley & Joseph, 2004). Moreover, numerous participants demonstrated adversarial growth in their descriptions of the psychological capacities and strengths they had developed as an outcome of CTA. These capacities and strengths enabled them to manage significant, complex life difficulties arising from their illness with more confidence. This is not to suggest that those who have not experienced CTA do not have the same capacity or skills to manage their psychosis. Rather, it

illustrates that some participants' abilities to adapt to and cope with past trauma and/or adversity enhanced this psychological capacity. However, the process of adversarial growth was both protracted and psychologically challenging for all participants. As one participant observed:

You train yourself to be different to what you already know. It's like you've got to learn to be a person. It's like you wake up and see who you are and its like 'well, I don't want to be this'. (1496)

## **6.5.3 Speculative Change**

It does mean different things, resilience, and [in] different contexts. (1496)

When asked to consider alternative personal realities during the 'magical thinking' exercise in the interviews, a number of participants (27%) confirmed that, although their CTA experience(s) had had a profoundly negative effect on their lives, they would not change these events if they had a choice. For example, one participant stated: 'I wouldn't have the skills that I've got now. So I don't know that I would change it [their experience(s) of CTA]' (1288). As I have described throughout this chapter, participants predominantly conceptualised CTA as a resilience-defining event. Many participants consistently reported that they had psychologically integrated their experiences of CTA: 'it made me who I am. It taught me that' (1546). Another said:

I wouldn't change anything because I wouldn't be the same person. I would be a different person. (1288)

Moreover, through the processes of reconciling these traumatic and/or adverse personal events, some participants reported that they had learnt the highly valued coping strategies

detailed in Theme One. The coping strategies enabled them to proactively manage their illness and the ongoing challenges it created in their lives.

As I have illustrated, the majority of participants primarily conceptualised CTA through a positive lens. While they acknowledged the psychological suffering of CTA, participants also perceived significant psychological gains from their experience(s). As I have also described throughout this chapter, they identified these psychological benefits as abilities and strengths that provided them with the confidence to manage their illness and complex lives. Some also referred to their heightened emotional capabilities, including empathy and assertiveness, which they attributed to their experience(s) of CTA. Many participants valued these psychological capabilities highly and they had become integral to their own sense of identity:

I don't think I would have had any compassion. How can you understand something if you don't go through it? You've got to experience it to know what it's like. If I had no problems or no trials and no trauma I wouldn't be the same person. (1686)

Similarly, one participant reported that the ability to be psychologically flexible and adaptable was a significant outcome of their CTA experience(s). It was also apparent that many participants' positive assessments of the skills and personality attributes developed through their CTA experience(s) had become integral to their notions of identity and self-worth. Consequently, they chose to retain their experience(s) of CTA, even when hypothetically considering alternative realities and futures. Some participants described living their lives in relatively positive and productive ways: 'I'm happy with the way my life is. I wake up every morning with a smile on my face now' (1530). Central to this optimism

was the confidence that they had the inner psychological resources and strengths to manage the effects of their illness, despite ongoing health and socioeconomic challenges.

However, participants also identified psychosis as a major negative factor in their lives and all eliminated it from notions of an alternative future. This is not surprising. As I described in Theme Three, the experience of psychosis was a recurring health, psychological and social concern for many participants. Numerous participants had developed proactive and effective management strategies that indicated high levels of resilience. However, maintaining their recovery required tenacity and energy. An indication of the ongoing demands of managing psychosis was reflected in one participant's preference for a future in which their capacity to manage their illness was enhanced:

If I could change anything speculative about my life, it would be where I could be stronger in life, to cope with things. (1469)

Consequently, when asked about what they would change in their lives, a common response was 'mental illness. Definitely!' (1688). One participant said:

Get rid of my illness. That would be number one straight away. Get rid of the bi-polar, the anxiety, the schizophrenia, and see what it's like normal. (1225)

### 6.5.4 Reconciliation, Post-Traumatic Growth and Speculative Change: Conclusion

Everyone has got it in them to overcome and be resilient. (1469)

Some participants' accounts of the positive psychological changes following CTA provided evidence of PTG. Participants identified indicators of PTG such as confidence to face new challenges, improved self-esteem and more optimistic attitudes. These findings

are congruent with the dimensions of psychological growth following trauma and/or adversity including an appreciation for life, personal strengths and positive changes in life priorities identified by Tedeschi and Calhoun (2004). Although the notion of the positive acceptance and reconciliation of trauma and/or adversity is not new (Pitt, Kilbride et al. 2007), Theme Four confirms that the experience(s) of CTA were life-defining events for individuals within the cohort. Participants described how CTA had influenced their psychological functioning, identity and sense of self. The interpretations of the positive psychological benefits that arose from their struggle with CTA did not diminish the difficulties they experienced reconciling themselves to these events. Rather, they illustrate that the majority of individuals were able to develop dispositions and positive coping capabilities in response to these challenges.

Moreover, several participants described how they applied the coping strategies they had learnt through managing the effects of CTA to maintain their recovery from psychosis. This ability to positively adapt to the additional challenges created by their illness is an example of participants' resilience capacity. Furthermore, as I described in Theme Two, the majority of the cohort had not engaged in counselling for CTA. Instead they had developed resilience through a process of adversarial growth that had severely challenged their psychological resources.

# 6.6 Discussion: Study Two

It [CTA] does impact on everyday things. (1469)

#### 6.6.1 Introduction

As I have described, I applied a qualitative methodology to investigate resilience in a sample of 27 participants with psychosis and CTA. The sample was drawn from the South Australian SHIP cohort. I established a large evidence base of participants' insights and understandings of CTA, psychosis and resilience. A number of participants identified CTA as a determining factor in the development of their resilience. Although they viewed CTA as a significant negative life event, they perceived psychosis as a dominant influence on their life trajectories and current functioning. For example, the personal management of psychosis created ongoing challenges resulting in high levels of physical and psychological disability for some participants. I analyse these topics in further detail below.

#### 6.6.1.2 The Interconnection between Themes

The thematic analysis of the Study Two data captured a range of participant perspectives. As I have stated, these perspectives defined the three primary themes (i.e. resilience, psychosis and CTA) and the corresponding sub-themes of this PhD research. I have also included an additional theme titled 'Illness Recovery and Speculative Change'. At the commencement of the qualitative data analysis process I anticipated that the primary themes would be independent of each other. However, further analysis revealed that participants alternated between discussing CTA, psychosis and resilience. This created an interconnection between the themes. It indicated that the experiences of CTA and psychosis affected individuals in psychologically complex and integrated ways. Therefore, although I have discussed the themes that emerged from the qualitative data analysis separately, where applicable I have highlighted the associations between CTA, psychosis and resilience. I propose that these links indicate interactions between complex

behavioural, social and cognitive factors. This leads to questions about the compartmentalisation of treatment approaches evident in some mental health services. Consequently, in Chapter 8 I will highlight a number of recommendations for integrated therapeutic approaches that move beyond a focus on individual disorders.

## 6.6.1.3 Participant Engagement in Study Two

The majority of participants were engaged in the Study Two interview process. A small number (n=3) were occasionally reticent to expand on personal reflections or to disclose specific opinions. Several participants (n=4) reported appreciating the opportunity to discuss their insights and perceptions about the effects of CTA and psychosis on their lives. Some also stated that they found the opportunity to discuss their experiences of CTA and psychosis in the interview cathartic. This level of participant engagement and positive responses to the interview experience suggest that there may have been scope to expand the role of participants in the research. For example, if participants had been provided with additional opportunities to discuss and validate interview transcripts, the richness of the interview data may have been enhanced. This may have consequently provided further insights into the lived experiences of CTA and psychosis and participants' understandings of resilience (see Chapter 9 for further discussion of the limitations of this PhD study and the potential for future research in the topic area).

### 6.6.2 Participant Conceptualisation of Resilience

While the role of participants in Study Two could have been expanded, analysis of the interview data nonetheless has provided a rich source of material for the investigation of resilience as a psychological, health and social phenomenon. As I have stated, although there was some variation, consistent patterns were evident in participants' definitions of resilience, views about how it was manifested, and the role of resilience in enhancing health, and psychological and social functioning. Some participants were unfamiliar with

the terminology of resilience. However, the most common conceptualisation across the cohort was that resilience was the ability to manage stress and overcome obstacles in life. This understanding is fundamentally aligned with the conceptualisation of resilience in the literature in the field.

As I have stated, the majority of participants attributed the development of their capacity to be resilient to their experience(s) of CTA. Their narratives illustrated how they had learnt positive coping skills managing the effects of CTA and the process of reconciling themselves to these highly distressing childhood experiences. Individual accounts of the experience of psychosis confirmed that resilience was one of several important factors in the management of the participants' health, and psychological and social lives. This included coping with the day-to-day challenges of living with psychosis and the impediments it created to living a life that was socially connected and economically sustainable.

The understanding that trauma and adversity may enhance psychological growth is not new (Tedeschi & Calhourn, 2004). However, evidence indicating that some individuals with CTA and a serious mental illness continue to grow psychologically in response to additional stress and adversity created by psychosis deserves consideration as a further research and practice issue. Fundamental to this issue is how clinical services recognise and consider the effects of CTA and bolster emotional strength and coping capacity as they manage the stress and adversity created by psychosis.

## 6.6.3 Resilience and Recovery from Psychosis

The Study Two data indicates that resilience is an important feature of the recovery from psychosis. As I have stated, resilience played a central role in how participants psychologically constructed their illness, managed its symptomology, and coped with the

limitations and demands it placed on their lives. Several participants also stated that they accepted their psychosis was a lifelong illness. As I have previously described, they identified a range of psychological and social competencies they had developed as an outcome of CTA prior to their onset of psychosis. They described how they applied these competencies to manage the complexity of psychosis and pursue their goals of economic and social participation in the community. It was evident that a number of participants had refined and extended these skills through the long experience of managing their illness. These skills included core resilience qualities of optimism, self-awareness, confidence and determination. As Anthony (1993) notes, these traits are fundamental to the maintenance of successful recovery from any type of mental or physical illness. Despite concerns about the future course of their illness, some participants expressed confidence in their ability to maintain their illness recovery. Accepting the often-disabling health and psychological effects of psychosis was part of the process of reconciliation and integration of their illness into their identities and lives.

However, the possibility that people with psychosis may develop and demonstrate resilient qualities without the experience of CTA requires consideration. This is because other factors aside from CTA are also likely to have contributed to the development of resilience. As I have previously noted, resilience development is contingent upon a broad range of individual social, genetic and psychological circumstances (Johnston-Wilder, 2010). Exploring the wide range of additional factors that potentially contribute to resilience in the research sample was beyond the capacity of this research. However, despite these limitations, Study Two provides firm evidence that, in this cohort, resilience was a factor in the recovery from illness. This finding is central to the aim of this PhD research of providing evidence that broadly informs mental health policy and practice. It is the basis of my proposal that, regardless of the experiences and processes that contribute to

the development of resilience, the identification and utilisation of a person's resilience capacities should be part of recovery-oriented mental health praxis. I discuss resilience in clinical mental health practice in more detail in Chapter 8.

#### 6.6.4 The Assessment of Resilience

Establishing the links between CTA, psychosis and resilience is dependent on the reliable assessment of resilience. As I have described, I used participant discussion and self-assessments of resilience taken from the face-to-face interviews to identify and describe how resilience was manifest. I then compared the results from participant self-assessments with scores from an individually administered quantitative measure of resilience utilising the Resilience Scale. The purpose of using both the qualitative interview data and the Resilience Scale was to determine whether these different methods of measuring resilience achieved similar results. Another was to identify whether the Resilience Scale was a suitable resilience measure that could be used in clinical mental health practice.

Although there were clear similarities between the results of the qualitative interview data and the Resilience Scale, some minor differences were apparent. The scores from the Resilience Scale for some participants indicated a lower level of resilience than was evident from the qualitative analysis of the same participants' Study Two interview data. For example, several participants discussed perceptions about their own resilience during the interviews in relatively positive terms, while their results from the Resilience Scale conversely indicated moderately low levels of resilience. While these differences were not profound, they suggest that the Resilience Scale may not be an entirely accurate measure of a person's perception of their resilience for some cohorts such as psychosis populations. Furthermore, the complexity of the lived experience of psychosis, and/or personally challenging events such as CTA, adds additional complexity to the administration and assessment of an instrument such as the Resilience Scale. I discuss the implications of this

further in Chapter 8, including a discussion about developing a measure of resilience specifically tailored for psychosis populations and the potential advantages such a measure may have in clinical mental health settings.

### 6.6.5 CTA, Resilience and Post-Traumatic Growth

As I have previously noted, research in psychology, medicine and related health and social disciplines consistently demonstrates that CTA can be a precursor to a range of significant physical and psychological conditions and disorders. However, these investigations have predominantly focused on identifying the negative effects of CTA. In this PhD research I have sought to extend the focus beyond identifying the negative effects of CTA to investigate how individuals may psychologically adapt and develop in response to highly distressing experiences such as CTA and the experience of living with a severe mental illness.

Thus, an important part of this PhD research was to compare the health, economic and social outcomes of a sample of CTA and non-CTA participants with a psychotic illness. The outcomes of this quantitative data analysis are detailed in Study One. Minimal differences in outcomes were found to exist between the two groups. This finding could be interpreted as indicating that CTA has little effect on psychological functioning and consequent health, social and economic outcomes. However this interpretation discounts the evidence from Study Two demonstrating that the experience(s) of CTA can also have positive outcomes for some individuals. As I have discussed, Study Two participants indicated that the most significant of these was the development of resilience. Therefore, an alternative interpretation of these findings takes into account the resilience characteristics of the CTA sample. It proposes that resilience is the mediating factor in the relationship between CTA and health, social and economic outcomes in some individuals. In this relationship, the positive effects of resilience on psychological functioning are

reflected in the health, social and economic outcomes of the CTA cohort. I suggest that the influence of resilience is significant enough to ensure that the CTA sample achieved similar health, psychological and social outcomes to the non-CTA cohort. Strengthening this interpretation is evidence from Study Two indicating that a number of participants also demonstrated PTG. This PTG may be a result of the psychological processes of adaptation and growth in response to CTA. The transformative psychological changes (such as a renewed sense of personal strength) integral to PTG (Tedeschi & Calhoun 2004) may have further enhanced participants' psychological functioning and consequent health, vocational and social outcomes.

Based on the above findings, I conclude that the experience(s) of CTA can lead to positive psychological outcomes that can assist individuals with psychosis to manage the complex health and psychosocial challenges in their lives. This position challenges the conclusions from the wider research field that have established links between CTA and predominantly negative health, psychological and social outcomes. However, I acknowledge that the conclusions reached in this PhD research need to be further tested and considered in relation to existing evidence. As other research has shown, the relationship between CTA and psychological functioning is complex, particularly in psychosis populations. Unravelling the links and interactions between these phenomena presents a range of challenges for researchers. However, understanding the connections and interactions between CTA and psychosis is particularly important for clinical mental health practice whose effectiveness is dependent on reliable, up-to-date evidence about the treatment of mental illness.

### 6.6.6 CTA and Clinical Mental Health Settings

As I have stated, the Study Two data analysis suggests that, for some participants, CTA was a resilience-enhancing psychological event that appeared to diminish the debilitating

impact of psychosis. However, participants' experiences of CTA were not acknowledged in clinical mental health settings. Consequently, the majority of participants were not engaged in any significant interventions regarding their CTA. The lack of acknowledgment of CTA in clinical mental health settings may have limited the opportunity to utilise and build on the resilience individuals had developed as an outcome of CTA.

As I have previously discussed, one of the impediments to identifying resilience in clinical mental health practice is a lack of agreement about ways of assessing resilience in this population. Generic mental health assessments (especially for first episode psychosis) that include the identification of CTA event(s) and an assessment of resilience may partly address this clinical practice issue. If these assessments are specifically tailored for mental health/psychosis populations they may provide a time-efficient way to assess individuals' resilience levels and CTA. In addition the limited acknowledgement of CTA, and the potential of resilience to enhance recovery, may also reflect a limited appreciation of the interrelationship between CTA, psychosis and resilience on the part of mental health services. Addressing this service gap requires further evidence and knowledge about these topics. This needs to be accessible, broadly disseminated, and able to be used for the development of guidelines for policy and clinical practice.

#### 6.6.7 Psychosis

All Study Two participants identified psychosis as the predominant health, psychological and social factor that defined how they lived their lives. Their accounts of the illness illustrated how some struggled to lead a life that they viewed as sustainable and fulfilling. Nonetheless, while some perceived psychosis as diminishing their capacity to live a quality life, the majority of participants were more optimistic about their capacity to manage its effects and maintain their recovery.

Participants' accounts of living with psychosis in Study Two need to be considered in relation to Study One, which confirms that psychosis has a negative effect in many domains of life. As research has demonstrated, health comorbidity remains a significant health and social challenge for psychosis populations (Dixon, Postrado et al. 1999) and Study One has drawn attention to the poor physical health of many SHIP participants. Poor health can be attributed to a range of comorbidities that require continuous clinical interventions and ongoing engagement with health services. This was reflected in many participants' personal experiences of ongoing health difficulties and their effect on their social and economic functioning. The effects of illness medication also created some health difficulties for many. In addition, the majority of Study One and all of the Study Two cohort lived in a community characterised by social disadvantage and high levels of poverty. For many, this poverty impacted on their vocational and educational opportunities and increased their social isolation. However, despite these obstacles, many Study Two participants continued to demonstrate optimism about their continuing illness recovery.

## **6.6.8 Illness Recovery**

Despite their acceptance of psychosis as a lifelong illness together with long experience of managing its symptomology, a number of participants voiced concerns about the possibility of becoming unwell. Anxiety about a reoccurrence of the illness created uncertainty and apprehension amongst several participants. These feelings are indicative of the traumatic nature of the experience of psychosis itself. This is particularly severe in the first stages of the illness when individuals experience psychological disintegration and disruption that often leads to confusion, emotional turmoil and shock (Lysaker & Lysaker, 2001). Consequently, the process of illness recovery requires acceptance, reorientation to self and reintegration during which individuals come to terms with the illness and their vulnerabilities. Therefore, illness recovery for participants was often a protracted, lifelong process (Wilken, 2007).

Several participants were familiar with the concept of illness recovery and its associated discourses. This can be attributed to their extensive engagement with clinical mental health services and their long experiences managing their illness. Many viewed their illness recovery as a process that began with an illness diagnosis and proceeded to successful illness management and social/economic integration. In describing their illness recovery, several participants identified the process of coming to terms with their diagnosis and the myriad of health, psychological and social consequences. Descriptions of the trajectory of their illness also illustrated how the psychological disintegration that accompanies the acute phase of a psychotic episode was often profoundly confronting and distressing. Moreover, participants described illness recovery as a protracted and continuing process.

Underlying participants' understandings of recovery was the awareness that the process involved accessing and further developing the psychological capabilities (hope, optimism, self-esteem, self-acceptance, coping skills and physical health) that enable recovery to occur. As I have previously noted, participants described how they applied (and continued to reinforce and practise) these capabilities in order to manage their illness, overcome stigma and cope with their vulnerabilities to achieve a fulfilling life. In combination with their tenacity and determination to stay well in the face of continuing challenges, this confirmed the psychological adaptability and resilience of the majority of Study Two participants. Some participants also indicated that mental health services were crucial to their illness recovery, particularly during the acute phases of the illness. The ability to manage their illness independently by being mindful of risk factors was important in managing the anxiety surrounding the possibility of a reoccurrence. Several participants saw that forming social and community connections in the later stages of their recovery process were crucial to establishing meaningful social roles. In summary participants

interpreted recovery as a process through which they gained independence in managing their illness, achieved a socially integrated life, developed a positive identity and contributed to life in their community.

However, not all participants viewed their illness through a recovery lens. A small group (n=3) viewed the health, psychological and social challenges of managing their illness as overwhelming. They regarded their illness as irrevocably damaging their lives. In terms of illness recovery, during the Study Two interviews this group demonstrated less optimism in their ability to manage stress and to recognise risk factors. They discussed having less confidence in the effectiveness of their medication and talked more about being socially isolated than the rest of the Study Two cohort.

## 6.6.9 Speculative Change, Psychosis and CTA

In considering preferred alternative futures, all participants envisaged a personal world without psychosis but not all would choose not to have experienced the CTA. Although many expressed determination and confidence in their ability to maintain their recovery from psychosis, all identified the illness as hindering their capacity to achieve a desired quality of life. Participants' focus on the negative effects of psychosis is not surprising. As I have discussed, the experience of psychosis can diminish a person's capacity to function psychologically, socially and economically. Moreover, despite long experience managing the illness, anxiety about a possible relapse of psychosis (i.e. experiencing a psychotic episode) was evident across the cohort. Consequently, the participants considered that the impact of CTA on their lives was less severe and less pervasive than the impact of psychosis.

Underlying this finding is the fact that a number of participants viewed CTA as a precursor to the development of several valued psychological assets. As I have described, they

identified specific positive coping skills they had developed through a process of adaption and reconciliation to CTA. These were important in the management of their psychosis symptomology and in pursuing more preferred futures. Secondly, a number of participants regarded CTA as an important aspect of their psychological development. Many viewed their ability to survive, recover and learn competencies from their CTA experience(s) with pride. This reflects the process of psychological adaptation to adverse circumstances through which they had integrated the experience(s) of CTA into a positive sense of self.

Thirdly, for the majority of Study Two participants, CTA occurred long before psychosis was manifest in their lives. The ongoing impact of psychosis may have minimised the severity of the psychological effect of CTA. As I have described, psychosis presented participants with numerous ongoing health and social challenges that were frequently physically and psychologically debilitating. It is possible that they assessed other life events such as CTA (regardless of psychological or physical severity) in relation to the continuing demands and challenges of living with psychosis.

### **6.7 Study Two- Limitations**

For Study Two, undertaking a mixed-method approach to investigating three complex and interrelated issues from a health, psychology and social perspective proved challenging. One of the limitations of Study Two was that it investigated the relationship between CTA and resilience in a psychosis cohort with a high CTA prevalence rate. While the research established that, in some instances, CTA was a resilience-enhancing experience, these results cannot be extrapolated to apply to other psychosis or mental health populations. Furthermore, although the Study Two interview cohort was relatively diverse, the research findings would have been strengthened by the inclusion of non-CTA participants. A comparison between the CTA and non-CTA cohorts utilising a similar research focus might have confirmed whether CTA was a significant determinant of resilience within the

complex interplay between the factors that may contribute to its development in this population. A comparison may also have identified further differences between the cohorts and provided additional insights about the lived experience of psychosis, resilience and illness recovery.

Another limitation of Study Two was that the qualitative data was based on self-reports. Additionally, much of the quantitative SHIP data was also based on self-reports. This may have compromised the reliability of the research conclusions. Although the SHIP interview tool has been shown to have satisfactory reliability with psychosis populations, there may be some limitations in its design regarding how participants self-reported their CTA histories. Retrospective reporting in both the SHIP study and in Study Two may make it problematic to draw strong cause and effect inferences regarding the individual resilience capacity of the research participants. Furthermore, the CTA-specific data from the SHIP cohort relied upon a single question that provided both quantitative and qualitative information that was non-specific. The number of participants who reported CTA in the SHIP cohort may have been affected by the ambiguity of the CTA question in the SHIP interview schedule (i.e. the type and timing of the CTA event).

The experience of the face-to-face interview, combined with the challenges of managing a severe long-term mental illness, may have influenced the capacity of some Study Two participants to consider other personal attributions in relation to their perceptions and experiences. For example, recall of the psychological effect(s) of CTA may have been tempered by more recent experiences of psychosis, which in itself can be a significant traumatic experience. Furthermore, the format and style of the interview may have influenced participants' responses to the interview questions. For example, questions about psychosis and/or CTA may have inadvertently linked these two topics in the minds of

some participants and possibly shaped their responses. Moreover, as I discussed in the reflexive statement in Chapter 3, the relationship between the researcher and participant in research is often unequal in terms of status and authority. Consequently, participants in Study Two may have provided responses to questions that they assumed fitted my research intentions.

Finally, there are some areas where the qualitative data used to inform the themes could have been enriched. For example, I could have used participant validation of the themes as a way of providing deeper insights into their experience(s) and insights. I did not invite Study Two participants to engage in further discussion or to validate the accuracy and completeness of interview transcripts. This validation may have enriched the themes and extended the scope of the research further. However, given the complex psychological and health status of the participant group, a broader exploration of their CTA experience(s) may have caused additional stress.

#### 6.8 Study Two: Conclusion

Analysis of the Study Two interview data highlights a range of participants' insights and understandings of psychosis, CTA and resilience. The themes that emerged from the interview data illustrate that resilience was determined by complex individual, psychological and social circumstances. While the majority of participants viewed CTA as a significant life event, they identified psychosis as their dominant and pervasive life challenge. Nonetheless, a number of participants identified positive outcomes from their experience(s) of CTA, including the development of the psychological capabilities and attributes that enabled them to better manage the symptomology of their psychosis. They viewed psychosis as having a significantly greater negative impact than CTA on their psychological, social and physical health, including their quality of life.

Nevertheless, this PhD research has demonstrated that some individuals who have experienced both CTA and have a diagnosis of severe mental illness can be resilient. This finding challenges deficit notions that position people who have experienced CTA and have a severe mental illness as not resilient. Resilience was evident in the research sample despite the uncertainty of living with a possible reoccurrence of psychosis and its oftensevere impact on participants' health, and economic and social functioning. Although the findings from this research require further verification, it has highlighted the relevance of resilience as a recovery tool for use in clinical practice.

A large body of literature in the field of resilience has focused on its importance for healthy psychological functioning. Programs and therapeutic processes for developing resilience have emerged over the years in a number of fields, including education and psychology. However, there has been limited research examining resilience in people with CTA and a psychotic illness. By identifying the links between CTA and resilience, this PhD research demonstrates that individuals can experience positive growth through a process of psychological adaptation to distressing circumstances. This evidence points to the importance of recognising the relationship between CTA and resilience in clinical mental health practice. However, this research also emphasises that CTA cannot simply be viewed as a precursor to resilience. In focusing on the positive outcomes that may arise from the experience(s) of CTA, I want to emphasise that both CTA and psychosis can create significant psychological stress and suffering for individuals. A discussion of positive psychological growth following trauma must always be considered in this context.

In Chapter 7, the paper titled: 'Psychosis, socioeconomic disadvantage and health service use in South Australia: findings from the Second Australian National Survey of Psychosis' is reprinted here in its entirety. This paper focuses on the SHIP data in the context of the

comparatively high level of social disadvantage evident in the South Australian SHIP cohort. Following this is Chapter 8, which discusses in detail the results and implications from the findings from both Study One and Study Two. In this chapter I examine the psychological, health and social implications of resilience further and its potential to influence recovery from psychosis. I also highlight the clinical mental health importance of resilience, including the potential for resilience to affect the trajectory of illness recovery and to influence clinical practice with this population.

# Chapter 7

# Psychosis, socioeconomic disadvantage and health service use in South Australia: findings from the Second Australian National Survey of Psychosis

# **Statement of Authorship**

Status of paper: Under review. PLoS One (submitted paper, 2nd May 2015).

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Name of Principal Author (Candidate)	Shaun Sweeney
Contribution to the Paper	Wrote the main manuscript, conducted the literature review and preliminary analysis of data and wrote the result and the discussion.
Overall percentage (%)	80%
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# **Co-Author Contributions**

By signing the Statement of Authorship, each author certifies that:

- the candidate's stated contribution to the publication is accurate (as detailed above);
- ii. permission is granted for the candidate in include the publication in the thesis; and
- iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Tracy Air
Contribution to the Paper	Supervised preliminary analyses, conducted the analyses of the final model, aided in writing the results section.
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Contribution to the Paper	Assisted with evaluating and editing the paper.
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Contribution to the Paper	Supervised development of the work, assisted with data interpretation and manuscrevaluation.
Signature	Date 19/6/15
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#### 7.1 Abstract

#### **Abstract**

#### 7.1.1 Aims

This paper explores the relationship between socioeconomic disadvantage, family/social supports, physical health, and consequently and health service utilisation.

#### 7.1.2 Methods

The paper utilises quantitative data from the 2010 Survey of High Impact Psychosis (SHIP) research project conducted in a socioeconomically disadvantaged region of Adelaide, South Australia. Participants (n=391, 42% male) were specifically asked about any experience of CTA. Respondents provided information about education, employment, physical health and health service utilisation.

#### 7.1.3 Results

The research found that the predictors of socio-economic disadvantage were less social engagement with family, higher BMI, greater self-reported use of emergency departments and less use of GPs for mental health reasons. There is also a complex relationship between socioeconomic disadvantage and poor health confronting individuals with psychosis.

#### 7.1.4 Conclusion

Mental health service usage for those with higher levels of socioeconomic disadvantage differs from those experiencing lower levels of socioeconomic disadvantage. The development of policy and practice that seeks to redress the socioeconomic and health inequalities created by this disadvantage should be an important focus for the mental health field.

# 7.1.5 Key Words

Psychosis, Socioeconomic Disadvantage, Health, Poverty, Health Service Delivery

#### 7.2 Introduction

Socioeconomic disadvantage is associated with a higher prevalence of and a higher mortality from most diseases, particularly the major chronic diseases such as heart disease (Glover, Hetzel et al. 2004, Young & Furler 2005). The concept of socioeconomic disadvantage can be applied to individuals or populations who reside in low-income circumstances, and who struggle to supply themselves and their families with food, clothing and shelter. This disadvantage can take multiple forms, including limited job security, poor social networks, low self-esteem, poverty, and fatalism (Brunner, 1997). As socioeconomic disadvantage can also include difficulties in accessing government income and social supports, such disadvantage is heightened for people with psychosis whose complex health needs require access to such services. Furthermore, the links between psychosis and socioeconomic disadvantage have been identified across diverse cultural, social and demographic contexts. Research has now established a clear relationship between poverty and psychosis (Topor, Andersson et al. 2014), prevalence rates of schizophrenia (Moser, 2001) and rates of admission for schizophrenia (Koppel & McGuffin, 1999). Additionally, people with a mental illness can experience lower levels of employment than the general population (Ramsay, Stewart et al. 2012). With regard to clinical characteristics that predict utilisation of services, the most common finding has been that psychosis is linked to a higher rate of utilisation of specialist services (Giel & Ten Horn 1982, Tansella, Micciolo et al. 1986). Given this, there is a need for information to enable the planning of and resource allocation for services where people with a psychotic illness present (Hansson, Muus et al. 1998).

There is extensive research examining the links between psychosis and poor health and social outcomes. However, there has been less research focusing on the relationship between psychosis, socioeconomic disadvantage (including homelessness, poverty and

social isolation) and the use of health services (Bindman, Tighe et al. 2002). For example, while psychosis can limit income capacity, it is less clear how this affects the level and type of health service usage rates of social engagement and the ability to effectively manage illness symptomology. Consequently, attempts to determine the most appropriate social policy, service practice mandates, and praxis in this area have lacked coherence. The relationship between the influence of socioeconomic disadvantage and the increase in the utilisation of community services such as mental health facilities needs to be examined further (Croudace, Kayne et al. 2000) and the causal links between psychosis and poor socioeconomic outcomes require further examination to strengthen the knowledge base regarding these links. Previous research has attempted to improve services that address the challenge of poor health and socioeconomic participation among persons with mental illness but have frequently failed to recognise that the experience of people with mental illness is often contextualised in disadvantaged social settings (Draine, Salzer et al. 2002). Additionally, the use of health and social services amongst psychosis populations can differ according to their socio economic status (Jablensky, McGrath et al. 2000). Therefore, understanding the relationship between the lived experience of psychosis and socioeconomic disadvantage has the potential to influence the development and implementation of health and social policy initiatives.

The contribution of this paper to the field of mental health is twofold. First, utilising quantitative data from the Survey of High Impact Psychosis (SHIP) project, the paper presents an overview of health status and level of socioeconomic disadvantage in a regionally representative psychosis population. Second, the paper examines the relationship between socioeconomic disadvantage and family/social supports, physical health and consequently, health service utilisation.

#### 7.3 Materials and Methods

#### 7.3.1 Subjects

The data for this study was collected during the SHIP research project in the northern suburbs of Adelaide, South Australia (Morgan, Waterreus et al. 2012). The northern suburbs<sup>21</sup> of Adelaide, South Australia, have 226654 residents in a geographical area of 814 square kilometres. The population age structure almost equals the national figures. Rates of single parent families are higher than the national average; unemployment is higher while labour force participation is slightly lower. Qualifications beyond high school are lower in this catchment (45.6%) compared with the national average (56.2%).

Trained interviewers, who were mental health clinicians and had worked in the local mental health services, conducted all of the interviews. The appropriate institutional ethics committees approved the study and all participants gave written informed consent.

#### 7.3.2 Assessments

The Psychosis Screener identified 1825 adults aged 18–64 years who were residents in the South Australian postcode catchment. These potential participants had been in contact with public mental health services in the 12 months prior to the survey and attempts were made to recruit all of these potential participants. Eight hundred and three were unable to be contacted, 16 were known to have died, 33 did not meet inclusion criteria due to inability to sufficiently communicate in English, 42 did not have capacity to give informed consent, and 507 refused. 1825 potential participants were identified during the SHIP census period

kilometre.

<sup>&</sup>lt;sup>21</sup> The northern suburbs of Adelaide consist of the cities of Playford, Salisbury, and Gawler, located in the northern region of metropolitan Adelaide, South Australia. The city of Gawler is located approximately 70 kilometres from Adelaide's CBD and is the most distant of the three council areas. The combined catchment area has an estimated resident population of approximately 230,000 within a radius of 815km. The population density of the catchment is 432.4 residents per

and 402 participants were interviewed. Further information regarding the method of the SHIP is detailed in Morgan et al. (2012).

#### 7.3.3 Statistical Analysis

Statistical analyses were performed using Stata, version 12 (StataCorp. 2011. Stata Statistical Software: Release 12. College Station, TX: StataCorp LP). The Australian Bureau of Statistics (ABS) Socio-Economic Indicators for Areas (SEIFA) Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD) was obtained for every participant's suburb and the percentiles were used as a proxy measure of socio-economic disadvantage. A low score on the SEIFA IRSAD is indicative of relatively greater disadvantage and a lack of advantage in general. A two-step model building procedure was used to determine variables associated with the SEIFA IRSAD. In the first step, we used univariate analyses (linear regressions) to examine whether the percentile measure of the IRSAD was associated with socio-demographic, physical health, social and health service utilisation measures. In the second step, we used multivariate regressions, including only variables that were associated with the SEIFA IRSAD at alpha  $\leq$  0.10 in the first step.

#### 7.3.4 Ethics Statement

Ethics approval for this research was obtained from the Human Research Ethics Committee of the Queen Elizabeth Hospital (Protocol number: 2009179).

#### 7.4 Results

Table 7.1 illustrates demographic and lifestyle factors from the SHIP cohort. The SHIP sample recruited in South Australia comprised 402 participants who screened positive for psychosis. There were 168 female participants (42%) and the mean age of the sample was 38.5 (SD=10.6) years. One fifth of the sample (20.9%) was currently married or in a defacto relationship. The average age that the sample left school was 16 (SD=1.3) years, while 43 per cent reported having a post-school qualification. The main source of income

for 92.5 per cent of the sample was a government pension. In the year prior to interview, 23.4 per cent were in paid employment; however, this figure was reduced to 16.2 per cent for paid employment in the past week, indicating the transient and short-term nature of employment for this sample. Seventy two per cent (n=290) of the sample reported being a current smoker. One hundred and sixty nine participants (42%) reported a lifetime history of alcohol abuse or dependence, while 47.7 per cent had a lifetime history of illicit drug abuse or dependence. Twenty three per cent of the sample had been victims of violence in the previous year, while 10 per cent had been charged for committing an offense. No significant relationships were found between any of these demographic and lifestyle factors and the SEIFA IRSAD.

Table 7.1: Socio-demographic and lifestyle from the SHIP sample

	Cl.: C 1 -		
	Ship Sample	0 65° : 4 (056) GE	a volvo
	(n=402)	β coefficients (95% CI)	p-value
Age and gender			
Female (n, %)	168 (41.8%)	0.40 (-4.92, 5.72)	0.88
Age (mean±SD, years)	38.5±10.6	-0.13 (-0.38, 0.11)	0.29
Education			
Age left school (mean±SD, years)	$16.0 \pm 1.3$	0.86 (-1.18, 2.90)	0.41
Post School Qualification (n, %)	174 (43.3%)	5.12 (-0.15, 10.39)	0.06
Marital status (n, %)			
Married/defacto	84 (20.9%)	-0.13 (-6.58, 6.33)	0.97
Income & employment (n, %)			
Main income source: pension	370 (92.5%)	-0.91 (-19.0, 0.86)	0.07
Paid employment (past year)	94 (23.4%)	4.71 (-1.47, 10.90)	0.14
Paid employment (past week)	65 (16.2%)	2.47 (-4.7, 9.6)	0.50
Smoking, drugs and alcohol (n,			
%)			
Lifetime alcohol	169 (42.0%)	-2.72 (-8.03, 2.59)	0.31
abuse/dependence			
Lifetime illicit drug	129 (32.1%)	3.32 (-2.30, 8.93)	0.25
abuse/dependence			
Current smoker	290 (72.7%)	1.01 (-4.89, 6.91)	0.74
Victimization and Offending (n,			
%)			
Victim of violence	93 (23.1%)	-2.71 (-8.93, 3.51)	0.39
Charged with an offence	40 (10.0 %)	2.28 (-6.49, 11.04)	0.61
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#### 7.5.1 Physical Health

As evident in Table 7.2 the mean BMI for the sample was 30.2 (SD=7.7), while the average waist circumference of the sample 105.5 cm (SD=19.3). Over half of the sample

(51.7%) met criteria for metabolic syndrome according to International Diabetes Federation criteria (International Diabetes Federation, 2006). Twenty four per cent already had cardiovascular disease or were at high risk for a cardiovascular event in the next 5 years based on the Framingham risk equation (National Heart and Lung Institute, 2002). The sample also had elevated levels of diastolic and systolic hypertension (50.5% and 40.1% respectively), cholesterol (51.2%), triglycerides (49.1%), and glucose (23.0%) that put them at risk of subsequent cardiovascular disease. A significant inverse relationship was found between the SEIFA IRSAD and both BMI and waist circumference, with lower socio-economic advantage being associated with higher BMI and waist circumference.

Table 7.2: Physical Health of the SHIP Sample

	Ship Sample (n=402)	β coefficients (95% CI)	p-value
BMI (mean±SD)	$30.7 \pm 7.7$	-0.34 (-0.7, -0.01)	0.049
Waist circumference (mean±SD, cm)	105.5±19.3	-0.16 (-0.30, -0.02)	0.023
Metabolic syndrome (n, %)	165 (51.7%)	0.48 (-5.5, 6.4)	0.87
CVD risk (n, %)			
Low	223 (66.2%)	0	-
Medium	19 (5.6%)	-0.66 (-13.4, 12.1)	0.92
High	13 (3.9%)	-9.76 (-24.9, 5.4)	0.21
Already has CVD	82 (24.3%)	-1.59 (-8.5, 5.3)	0.65
Diastolic hypertension (≥ 85 mmHg)	203 (50.5%)	0.43 (-4.8, 5.7)	0.87
Systolic hypertension (≥ 130 mmHg)	161 (40.1%)	-2.01 (-7.4, 2.2)	0.46
Elevated Cholesterol (n, %)	169 (51.2%)	2.16 (-3.7, 8.1)	0.47
Elevated triglycerides (n, %)	162 (49.1%)	-3.75 (-9.6, 2.1)	0.21
Elevated glucose (n, %)	76 (23.0%)	0.96 (-6.0, 8.0)	0.79

# 7.5.2 Social Networks and Support

A large percentage of participants (82.3%) reported frequent contact with their family (Table 7.3). While most participants (87.1%) reported having someone to rely on and over two-thirds reported that they had at least one person they could confide in, nearly half of the sample (49.3%) felt they needed or wanted more friends and reported experiencing loneliness (81.6%).

Many participants appeared to experience difficulties in maintaining positive social and emotional relationships. For example, 47.3 per cent reported dysfunction in socialising, and 12.0 per cent reported having no friends. A significant relationship was found between the SEIFA IRSAD and daily contact with family, with higher socio-economic advantage being associated with a greater level of contact with the family. A significant inverse relationship was found between the IRSAD and dysfunction in socialising, with lower socio-economic advantage being associated with greater social dysfunction.

**Table 7.3: Social Contact in the SHIP Sample** 

	Ship Sample		
	(n=402)	β coefficients (95% CI)	p-value
Daily contact with family	287 (71.6%)	6.54 (0.8, 12.3)	0.027
Someone to rely on	350 (87.1%)	6.80 (-0.99, 14.6)	0.087
No-one to confide in	72 (18.1%)	-5.51 (-12.3, 1.30)	0.11
Wants more friends	198 (49.3%)	0.78 (-4.5, 6.0)	0.77
Has no friends	48 (12%)	-4.96 (-13.1, 3.1)	0.23
Experienced loneliness	315 (81.6%)	-4.82 (-11.8, 2.1)	0.17
Dysfunction in socialising	190 (47.3%)	-6.05 (-11.3, -0.8)	0.023
Experienced stigma	145 (36.2%)	0.29 (-5.2, 5.8),	0.92
Fear of experiencing stigma (n=145)	81 (56.6%)	-0.85 (-8.2, 9.9)	0.85

#### 7.5.3 Health Service Use

Health service utilisation in the year prior to interview by participants was high, and they relied heavily on the public system for mental health services (Table 7.4). Forty-one per cent of the sample reported having a mental health related inpatient admission in the previous year, while 42 per cent reported attending an emergency department for a mental health reason. Twenty-two per cent reported at least one involuntary inpatient admission. However, despite 86 per cent using outpatient or community clinic services, only 43 per cent reported having a case manager in the public health services. GPs also bore the brunt of health care provision, with nearly 63 per cent of participants reporting they had visited a GP in the previous year for a mental health related reason. Emergency department

attendance for mental health reasons was found to be significantly associated with less socio-economic advantage.

**Table 7.4: Health Service Utilisation in the SHIP Sample** 

	Ship Sample		•
	(n=402)	β coefficients (95%	p-
		CI)	value
Inpatient admission, any	209 (52.0 %)	-2.00 (-7.2, 3.3)	0.46
Mental health	165 (41.0%)	-2.66 (-8.0, 2.7)	0.33
Physical health	72 (17.9%)	2.51 (-5.0, 10.0)	0.51
Number of inpatient admissions in past year (mean±SD)	1.01±1.9	-1.16 (-2.5, 0.20)	0.095
Involuntary admission	90 (22.4%)	-0.49 (-6.8, 5.8)	0.88
Community treatment order	66 (16.4%)	1.60 (-5.5, 8.7)	0.66
Emergency department attendance	230 (57.2%)	-3.39 (-8.7, 1.9)	0.21
Mental Health	169 (42.0%)	-5.36 (-10.6, -0.06)	0.047
Physical Health	100 (24.9%)	-0.02 (-6.1, 6.0)	0.99
Outpatient/community clinic	359 (89.3%)	-4.10 (-12.6, 4.4)	0.34
contact			
Home visit, any	208 (51.7%)	0.27 (-5.0, 5.5)	0.92
Crisis related	47 (11.7%)	-1.66 (-9.8, 6.5)	0.69
Routine visit	165 (41.0%)	3.04 (-2.3, 8.4)	0.26
Case manager (public health services)	173 (43.0%)	2.07 (-3.2, 7.4)	0.44
GP visits, any	368 (91.5%)	1.83 (-7.6, 11.3)	0.70
Mental Health	252 (62.7%)	4.51 (0.9, 9.9)	0.10
Physical Health	298 (74.1%)	-1.09 (-7.1, 4.9)	0.72
No of GP visits (mean±SD)	12.4 (16.2%)	-0.21 (-2.7, 2.3)	0.87

#### 7.6 Discussion

The SHIP data illustrates a complex relationship between psychosis, socioeconomic disadvantage and poor health outcomes. Mental health service usage for those with higher levels of socioeconomic disadvantage differs from those experiencing lower levels of socioeconomic disadvantage. For example, self-reports of emergency department use in the context of mental health crisis was evident in the cohort with higher levels of socioeconomic disadvantage, as was their lack of engagement with a GP for their management of mental health. Overall, the cohort reported high rates of physical health comorbidity as well as high levels of substance use (see Table 7.1). Furthermore, socioeconomic disadvantage appears to have exacerbated the poor physical health of participants in the SHIP cohort. Thus, the relationship between socioeconomic factors and

health outcomes are likely to be significant in determining the use of mental health and social services. The health and socioeconomic challenge of psychosis appears to have prevented a significant number of SHIP participants from engaging in healthy physical and social functioning, and economic participation in daily life. This includes engaging in paid employment or participating in other social and economic roles. Hence, psychosis can be viewed as an important factor in determining social and economic disadvantage for this group.

For primary care settings, working with populations experiencing psychotic illness and the complex health and social difficulties the illness presents has some challenges. The higher level of emergency department usage, primarily for illness management and/or crisis intervention by those with higher levels of socioeconomic disadvantage highlights the complexity of this issue. Services such as emergency departments cannot provide clinical input other than addressing immediate psychosis symptomology and medication management. For those living in poverty with limited access to family or social supports, emergency departments are the primary source of medical support instead of GPs or other preventative mental health services. Additionally, the greater risk of comorbid illness as a result of poor physical health (e.g. higher BMI or cardiovascular disease) can exacerbate the pressure on services to provide effective health outcomes, particularly when access to preventative health care (e.g. general practitioners) is restricted by socioeconomic disadvantage.

In summary, people with high levels of socioeconomic disadvantage were more likely to use emergency services for mental health reasons. This might be reflective of the lack of capacity to engage with health services or to manage comorbid illnesses; however it could suggest differences in the availability of economic resources to access paid services such

as GPs. They also accessed GPs less for mental health reasons, and had fewer family/social supports on which to draw. Consequently, the development of policy and practice that seeks to redress the socioeconomic and health inequalities created by this disadvantage should be an important focus for the mental health field. This paper also highlights the complex relationship between socioeconomic disadvantage and poor health confronting individuals with psychosis. The results are also congruent with much of the social and health literature indicating that people with a psychotic illness are more likely to reside in public housing (Holmes, Hodge et al. 2008), receive a government income/pension, and experience economic disadvantage and social isolation (Boydell, Van Os et al. 2004, Burns & Esterhuizen 2008). While mental health services seek to provide strong clinical and nonclinical intervention for psychosis treatment, less focus is applied to enhancing illness recovery through socioeconomic engagement and participation. However, effective clinical mental health support and interventions for individuals requires a coordinated and robust mental health system supported by social as well as health policy that places a priority on addressing socioeconomic disadvantage in mental health cohorts. Such a system would provide accessible treatment programs and linked pathways to illness recovery and diminish the pressure on the delivery of health services.

#### 7.7 Limitations

There are limitations with this study. As our data rely on retrospective self-report, the accuracy of the reporting of health service utilisation, or health in general, may be affected by recall bias. Another limitation is that using an area level measure such as the SEIFA as a proxy measure of individual level disadvantage assumes that the relationships observed for areas hold for individuals, and this may not be the case. Even in the most disadvantaged areas, there will be individuals who are less disadvantaged than others. However, given that the communities in this catchment area are resource poor, it is possible that area level disadvantage could contribute substantially to individual

disadvantage. It should also be noted that the cross-sectional nature of this study limits the conclusions that can be derived from the data, and while a cohort study would be more appropriate to assess long-term socio-economic trajectories, it was beyond the scope and budget of the current study. Additionally, further research into the links between psychosis, poor health and health service utilisation is required. How psychosis populations psychologically manage the intersections between these factors, including the need to maintain illness recovery, is a complex question that can only be addressed through comprehensive long-term research.

#### 7.8 Acknowledgements

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#### 7.9 Funding

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#### 7.10 Conflict of Interest

The authors report no conflicts of interest. The authors alone are responsible for the content and the writing of the paper.

## **Chapter 8**

## **Research Findings and Contributions**

#### 8.1 Introduction

In this chapter I summarise the findings and contributions of this research. I contextualise these research findings and contributions in the context of the wider research and mental health practice fields. I give prominence to the effects of CTA on psychological resilience and recovery from psychosis. In the first section I examine the findings in relation to current research in the field of CTA, resilience and psychosis. I identify and discuss the implications of the research findings and their contribution to the fields of mental health practice, policy development and future research.

#### **8.1.1 Research Context**

As I discussed in the Chapter 2, psychological resilience has been investigated across a wide range of disciplines. A strong empirical and conceptual base now confirms the importance of resilience for optimum health, and psychological and social functioning (Masten 1994, Masten 2001, Bonanno 2004, Bonanno 2005, Bonanno & Mancini 2008). However, the study of resilience in people with a mental illness has not been a primary focus of health, psychological or social research. Major contributors to the resilience field such as Bonanno have predominantly examined resilience in relation to child development and educational contexts. Consequently, less attention has been given to examining the relationship between resilience and such areas as psychosis and CTA. The vast body of research in this area has tended to focus on the manifestation of psychosis on health and psychosocial outcomes. As Campbell-Sills et al. (2006) suggest, this can be attributed to a longstanding focus on disease and pathology in the field of mental health.

Although the study of resilience in people with psychosis and CTA is limited, a small

number of studies have investigated resilience in people with a mental illness. For example, Johnson, Gooding et al. (2010) explored how psychological capacities such as resilience can limit vulnerability to risks such as suicide. In addition, Tait, Birchwood et al. (2004) examined the role of coping strategies in self-managing mental illness. The development of self-protective skills following the experience of trauma and/or adversity has also been explored in people with a psychotic illness (Kim, Song et al. 2013). As I highlighted in Chapter 6, participants in Study Two identified coping and self-protective skills as indicators of resilience and integral to the self-management of psychosis. Optimism and hope have also been identified as dimensions of resilience and as positive motivators in the course of recovery from psychosis (Wilken, 2007). One of the defining characteristics of the Study Two cohort was participants' optimism and aspirations for a positive future despite their CTA experiences and the continuing stressors related to their psychosis.

Although the findings from this PhD research require verification, they have addressed a knowledge gap in the field and contributed a mental health perspective to understanding CTA and resilience. Furthermore, participants' experiences and insights were central in the investigation. This aspect of the research contributes a unique consumer perspective to understanding the complex phenomena of CTA, resilience and psychosis. A significant finding from this research is that some people with psychosis and the experiences of CTA are resilient and live functioning lives. This suggests that CTA is a precursor to both negative and positive psychological and health outcomes. Emanating from these findings is the proposal that a more intentional focus on the positive outcomes of CTA in clinical practice has the potential to accelerate and prolong recovery from psychosis. Integral to this concept is an understanding that the experience(s) of CTA severely challenges an individual's adaptive responses. CTA experiences therefore engender high levels of psychological distress that can lead to severe physical and psychological consequences for

some people. These research findings can therefore be examined in relation to a substantial body of other research that has established significant links between CTA and poor psychological, social and physical outcomes. This includes the development of psychiatric disorders. Thus, the insights provided about the relationship between CTA, resilience and poor outcomes might explain why the findings from this PhD research contradict some of this evidence from the wider research field.

#### 8.1.2 Research Aims and Methods

As I have described, the central aim of this research was to examine the relationship between CTA, psychosis and resilience. In order to achieve this aim, I investigated the prevalence of CTA in a representative psychosis sample. I examined perceptions of resilience and how it was manifest in the research cohort. I also explored the influence of resilience on functioning and recovery from psychosis. Fundamental to the purposes of my research was identifying the implications of the findings for clinical practice.

My research methodology comprised two studies. I established the research context through a quantitative examination of the SHIP database. I identified the prevalence and effects of CTA in the research sample. I also explored the effects of psychosis on health, economic, psychological and social functioning. I conducted a qualitative investigation to explore whether CTA was a possible precursor to the development of resilience. Participants' insights and understandings of CTA, psychosis and resilience provide clear evidence of the complex interrelationships between these phenomena and the central role of resilience in recovery from psychosis.

#### 8.1.3 Finding One: Prevalence and Significance of CTA

The quantitative analysis of the SHIP data identified the prevalence of CTA within the South Australian sample as high in comparison with the general population. High prevalence rates of CTA within psychosis populations are well established (Janssen, Krabbendam et al. 2004, Spauwen, Krabbendam et al. 2006, Morgan & Fisher 2007). Nearly 60 per cent of all SHIP participants self-reported a traumatic and/or adverse event at some time in their childhood. This compares with a general CTA population rate estimated at approximately 25 per cent (Costello, Erkanli et al. 2002).

Comparisons between the CTA and non-CTA participants in the Study One data failed to indicate significant differences in health, socioeconomic and psychosocial outcomes. In many of the categories related to psychological and health functioning there was little or no indication that CTA adversely affected how participants functioned or recovered from psychosis. There was also no evidence that CTA negatively influenced vocational, economic or social participation. However, some small differences were evident in educational attainment, school completion rates,<sup>22</sup> employability and vocational outcomes between the CTA and non-CTA groups. Overall the Study One analysis of the South Australian SHIP data indicated that the negative effects of CTA on individuals' psychosocial and health outcomes were less significant than anticipated.

Study Two established that participants lived functioning lives despite the severe effects of their psychosis and their history of CTA. A high level of resilience was evident across the majority of the sample. A significant finding was that participants' attributed their resilience to experience(s) of CTA. There is a correlation between high resilience and the health, social and economic outcomes of the CTA sample. This points to resilience as a possible mediating factor in the relationship between CTA, psychosis, and poor health and psychosocial outcomes. As I have stated, the findings from this PhD research raise some questions regarding the correlations between CTA and a range of poor outcomes

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<sup>&</sup>lt;sup>22</sup> Completion of secondary school in the general population.

established in the larger research field. These correlations include the potential for developmental deficits (Nolin & Ethier, 2007), poor developmental outcomes (Kim & Cicchetti, 2003) and high-risk behaviours, including substance use (Evren, Kural et al. 2006). High utilisation of health services has also been noted among people with psychosis and a history of CTA (Dube, Miller et al. 2006). Links to physical illnesses such as eating disorders (Wonderlich, Brewerton et al. 1997), irritable bowel syndrome (Kendall-Tackett, 2000), and autoimmune disorders (Mulvihill, 2005) have also been established. CTA is also correlated with psychiatric disorders such as major depression (Lizardi, Klein et al. 1995) and multiple personality disorders (Katon, Sullivan et al. 2001).

However, as Read, Fink et al. (2008) suggest, more research is required to identify the specific biological, social and psychological mechanisms that link CTA and psychosis. In addition, some researchers in the field have challenged the strength of the correlation between CTA and poor outcomes. In particular, questions have been raised about the associations between CTA (particularly trauma and/or adversity such as CSA, physical abuse and interpersonal violence) and a range of adult psychiatric disorders (Morrison, Frame et al. 2003). For example, Spataro, Mullen et al. (2004) assert that the association between CTA (in this instance child sexual abuse) and schizophrenic disorders in later life has not been comprehensively established. The researchers assert that CTA is often enmeshed with other forms of adversity as well as family, social, psychological and biological factors that mediate its influence. These questions highlight the complexities involved in identifying links between multiple factors, establishing significance and attributing causal relationships in the relationship between CTA and psychosis.

Furthermore, investigating the complex web of health, psychological and social factors involved in the relationship between CTA and resilience in mental health populations

creates significant research challenges. These are reflected in the design of this study and need to be considered when reviewing its findings. For example, there is a possibility that the level of resilience in the Study Two participant group was higher than in other individuals with psychosis. It is possible that a psychologically resilient person may have been more likely to participate in this research due to their capacity to cope with and engage in what can be a psychologically demanding interview process. Therefore, the psychological profile of the Study Two cohort may not be representative of other psychosis/CTA samples. In addition, the health, psychological and social effects of psychosis can be pervasive and these might have obscured some of the differences between the CTA and non-CTA samples. These limitations mean that caution is required when generalising the findings from this research to other psychosis groups. I discuss this topic and other research limitations further in Chapter 9, section 9.4.

# 8.1.4 Finding Two: Prevalence and Significance of Psychological Resilience and Post-Traumatic Growth

As I have described, I identified resilience through a qualitative analysis of the Study Two interview data and the results of an individually administered Resilience Scale. The majority of Study Two participants attributed their resilience to their experience of coping with CTA. Their understandings of the construct, as well as their insights and descriptions of its development and manifestation, confirm the centrality of resilience in their lives. The majority of participants identified resilience as a crucial factor in their ability to manage their psychosis and maintain confidence in their ongoing recovery. A number provided descriptions of the competencies, behaviours and dispositions they considered constituted resilience. Nonetheless, further research is required to establish how resilience is manifested in this population. Additionally, in this PhD research I did not examine the dimensions of resilience that are most significant in the successful management of psychosis in any depth. As I have stated, participants in Study Two emphasised coping,

self-protection and strong self-esteem when they defined resilience. Therefore further research that clearly establishes the dimensions of resilience most critical in recovery from psychosis would assist in the development of resilience-enhancing therapeutic techniques and programs for clinical settings.

As I have stated, despite the highly distressing nature of their CTA experiences, the majority of participants in this research indicated that they were reconciled to these experiences. Moreover, analysis of the interview data in Study Two suggests that some participants may have demonstrated post-traumatic growth (PTG) in the aftermath of CTA. As I discussed in the literature review, PTG is the profound, positive psychological change experienced as a result of a struggle with highly adverse circumstances (Tedeschi & Calhoun 2004). Concepts relating to resilience and PTG are sometimes used interchangeably. However, PTG is conceptualised as more than the development of competencies that enable individuals to manage adversity positively. It is a deeply transformative process that creates psychological change including an enhanced ability to relate to others, an appreciation of life, spiritual changes and an appreciation of one's strengths (Tedeschi & Calhoun 2004). Indicators of PTG in Study Two were participants' heightened sense of personal competency and their focus on the positive aspects of their lives, particularly family and friendship networks. However, whether PTG was an outcome of some participants' experiences of CTA in this research needs to be considered in relation to the highly distressing experience of psychosis. It is well documented that part of the initial experience of psychosis is psychological disintegration, disconnection, loss of control and shock (Addington, Coldham et al. 2003). As CTA events occurred prior to participants' psychosis, it is therefore possible that the PTG reported by some participants was influenced by their recovery from psychosis rather than their CTA experiences.

#### 8.1.5 Finding Three: Social Disadvantage, Psychosis and the SHIP Cohort

Study One establishes that the effects of psychosis on participants' health, and economic and psychosocial functioning were significant. Study One highlights that a high percentage of the South Australian SHIP cohort experience social disadvantage and poverty. Almost the entire South Australian SHIP cohort resides in suburbs where socioeconomic disadvantage is prevalent. The majority are unable to participate in paid employment either as a direct consequence of psychosis or other health and social factors associated with their illness. Most access income and supported housing and experience difficulties in providing for their basic needs. The majority of the cohort also access community health and social services for support. These findings are consistent with evidence from the larger Australian SHIP study, demonstrating that people with a psychotic illness are more likely to reside in public housing, receive a government income/pension, and experience social isolation and loneliness (Morgan, Waterreus et al. 2012). The combined effects of poverty and social disadvantage are reflected in social exclusion, which can be a reality in the lives of people with a psychotic illness. These effects potentially hinder illness recovery and preclude individuals from establishing meaningful social roles.

#### 8.1.5.1 Psychosis and Physical Health Outcomes

Study One highlights that the physical health of participants in the South Australian SHIP cohort is generally poor. The data indicates that participants experience complex health problems such as high rates of obesity, diabetes and cardiovascular illnesses. Elevated levels of cardio-metabolic risk factors, which are evident in the SHIP population, can result in increased morbidity and mortality. Study One also identified some of the contributing factors to these risks, including smoking, drug and alcohol use, the side effects of medication, and poor lifestyle. For example, over 75 per cent of SHIP participants had a body mass index in the overweight or obese range, with almost half in the obese range. In comparison, data from the 2007 National Survey of Mental Health and Wellbeing indicates

that 34.2 per cent of the general population are overweight and 21 per cent obese (Slade, 2010). In people with psychosis, poor physical health can compound the burden associated with mental illness and diminish the capacity to establish meaningful vocational and social roles in their communities.

#### 8.1.6 Finding Four: Clinical Mental Health Services and CTA

Nineteen of the 27 Study Two participants reported that CTA was not addressed with any form of clinical intervention in their engagement with mental health services. Participants were not certain whether their disclosure of their CTA events was documented in their mental health treatment plans. Consequently, the role and impact of CTA in the development of resilience and its association with a heightened capacity for illness recovery may have been clinically overlooked. This oversight may have the potential to compromise the effectiveness of the clinical treatment process. An essential part of this process is the assessment of the competencies that an individual brings to their recovery and the identification of the events to which these are related. Moreover, as I have described, there is a high prevalence of CTA in psychosis populations. Failure to address the psychological effects of CTA in clinical mental health interventions may disregard a significant factor in the aetiology of psychosis and potentially limit treatment effectiveness.

## 8.1.7 Finding Five: Psychological Resilience Measures

As I have previously described, I considered three available quantitative measures for the assessment of resilience in the Study Two cohort. Following the pilot study I selected the Resilience Scale, as it appeared to be the most suitable measure with this research population. However, a number of participants had diminished cognitive capacity and language comprehension skills, and/or displayed varying levels of psychotic symptomology that potentially diminished their capacity to complete the scale accurately.

In addition, the Study Two sample size was small. As the prevalence of cognitive and comprehension deficits in psychosis populations is higher than for the general population (Pelletier, Achim et al. 2005, Schooler, Roberts et al. 2008), I suggest that the Resilience Scale is not an entirely reliable measure of psychological resilience for this population. This may have some implications for clinical mental health practice. For example, if resilience-based interventions and supports are to be developed for use with psychosis populations, the effectiveness of such interventions are contingent upon the identification and development of the psychological resources individuals require for illness recovery.

#### **8.2 Research Contributions**

#### 8.2.1 Introduction

In this section I identify the contributions of the research findings to the field of mental health practice and research. I present these contributions through the health and psychosocial perspective that has defined my investigation of psychosis, CTA and resilience. In discussing these research contributions, I will refer to current mental health treatment paradigms, practices and policies. I also include strategies to develop resilience and enhance recovery in clinical practice.

The contributions offered in this PhD research come from my perspective as a researcher who sees the potential of this research to advance mental health clinical practice. As I have described, these perspectives have been influenced by a long history as a mental health clinician working in a range of inpatient and community mental health settings. However, they are balanced by a pragmatic view that comes from the experiences of a clinician acutely aware of the constraints that limit the capacity of services to deliver quality care and intervention in disadvantaged communities. I therefore identify the service and clinical constraints that impede a more intentional focus on CTA and resilience in clinical practice.

I offer initiatives that have the potential to address these constraints. Both are intended to promote discussion and debate about the effectiveness of therapeutic treatments for psychosis, case management and counselling for consumers with psychosis and/or the experience(s) of CTA.

#### 8.2.1.1 Research Context

The majority of participants' accounts of their life experiences identified CTA as a significant event that was a determinant of resilience. They also identified resilience as a factor in how they viewed their recovery from psychosis and managed ongoing psychosocial stressors. For some, CTA led to transformative psychological change that comprises PTG (Ungerleider 2003, Calhoun & Tedeschi 2006, Steele & Kuban 2011). The findings from Study Two confirm the widely accepted theoretical position that both PTG and resilience are markers indicating positive psychological adaptation to extremely stressful events (Hobfoll, Hall et al. 2007). However, despite the high prevalence of CTA in the South Australian SHIP sample, the CTA experiences of participants and the corresponding PTG/resilience they developed from these experiences appear to be underutilised as a resource for recovery in clinical mental health practice. This raises some questions about how a focus on resilience may increase the effectiveness of services provided for people with psychosis and CTA. It also highlights the opportunity to develop clinical mental health practices that extend beyond the traditional focus on illness symptomology towards a stronger emphasis on psychosocial clinical input and consumer care.

However, in presenting the research contributions I suggest that some caution regarding the concept of CTA, resilience and PTG is required. The proposal that CTA promotes resilience and growth in all individuals is open to misinterpretation. As I have stated, there is wide agreement in the field that resilience and PTG can result from an individual's

adaptive response to trauma and/or adversity. However, CTA cannot merely be seen as a precursor to resilience. The psychological distress created by CTA may be integral to the development of resilience in some people. However, the assumption that one inevitably follows the other is false and potentially harmful (Tedeschi & Calhourn, 2004). Moreover, as I have previously noted, resilience development is not solely contingent upon the experiences of trauma and/or adversity. Research has also shown that individuals can develop resilience in positive, psychologically enabling environments (Hobfoll, Hall et al. 2007) without the experience(s) of trauma and/or adversity.

#### **8.2.2** Contribution One: Clinical Service Initiatives

In view of the high prevalence of CTA in the South Australian SHIP cohort, I propose that clinical mental health intervention and support should place an increased emphasis on the identification of CTA. In addition, I suggest that increased consideration should be given to how resilience can be more effectively utilised as a mental health clinical resource in recovery practice. This suggestion is congruent with the recovery mandate of current mental health services. As I have stated, recovery practice emphasises the development of psychological competencies such as coping and problem solving that enable consumers to achieve independence, self-esteem and a meaningful life while living independently in their community.

However, I emphasise that there are no simple solutions to ensuring that clinical mental health services become more responsive to the needs of consumers with a history of CTA. There are complex practice implications that need to be addressed for this to occur. A fundamental question that arises when considering the practice implications of this research is how people with a CTA and psychosis are constructed or 'positioned' within mental health services. Effective implementation of the above proposals would require clinicians to assess an individual's CTA history and corresponding resilience capacities

during the process of developing care plans and engaging consumers in their recovery. Service providers therefore would need to view CTA and resilience as potential psychological 'assets' that can be utilised in clinical practice. I posit that these underlying views of consumers' psychological strengths and potential for recovery are reflected in service cultures, organisational structures, clinical paradigms and practice. These, in turn, influence the service experiences of consumers, particularly their engagement and confidence in the capacity of services to support and sustain their recovery.

As I noted in the introduction to this research, the lack of emphasis on CTA and resilience in both research and clinical practice may reflect an assumption that people with CTA and psychosis are not resilient. This assumption may be strengthened by the prevailing emphasis in current research on the relationship between CTA and negative psychological and health outcomes previously described. It may be reinforced by the extensive research into human functioning that has been dominated by disease-focused medical models that have neglected the strengths, talents and virtues of the individual (Shiner & Masten, 2012). Finally deficit assumptions may be perpetuated if services do not have the resource capacities to extend their focus beyond illness management to fully consider the positive psychological capabilities that can accelerate and sustain an individual's recovery.

However, in order to implement the recovery mandate that defines mental health service provision across Australia, practitioners need a strengths-focused view of the consumer and their potential for recovery. I suggest that when consumers are positioned in relation to their strengths rather than their deficits, mental health services are more likely to implement practice mandates that have a strengths-focused, recovery orientation. As Wilken (2007) notes, practitioners who are most helpful in supporting recovery have strong beliefs in achieving positive outcomes for consumers. Moreover, they express hope

and confidence in the capacity of individuals to recover from their illness. Therefore, professional dialogue about the role of CTA and resilience in recovery may need to explore whether there is congruence within services between recovery mandates and clinical practice. This would include how psychosis, CTA and recovery are defined by practitioners, services and systems and be informed by the service experiences and perspectives of consumers.

However, my proposal that there should be a more intentional focus on CTA and resilience development in clinical practice needs to be considered in relation to the finding from Study Two indicating that the majority of participants were not concerned that their CTA experiences were unacknowledged and/or addressed by clinical services. Only three participants were critical of this oversight. As I stated, this finding can be attributed to the dominant role of psychosis in participants' lives. Although most Study Two participants indicated that they were functioning well, they viewed psychosis as their primary life challenge and regarded the continuing management of their symptomology as a priority. In addition, the majority of Study Two participants indicated that they were reconciled to their CTA experiences.

This finding raises the question whether a heightened clinical focus on CTA is congruent with the needs of consumers. However, as this research has demonstrated that CTA can be a precursor to the development of positive psychological outcomes, I argue that the acknowledgement of CTA and its effects has a place in clinical practice for some people. If CTA is acknowledged as an antecedent to potentially positive psychological outcomes, the emphasis in clinical practice would shift from exploring past reconciled CTA to enhancing the psychological capabilities that consumers may have developed in response to those events. As participants in Study Two described, these capabilities were fundamental in

how they managed their psychosis and maintained their recovery. A focus on the identification and development of these capabilities would therefore be congruent with the needs of consumers. It also has the potential to enhance, and further develop, strengths-based therapeutic practice as the core of mental health recovery mandates.

A strengths-based clinical mental health focus does not negate the importance of acute care for people with a psychotic illness. As I discussed in Chapter 2, the initial phase of psychosis leads to psychological disintegration of the self that can create psychological shock and trauma. Many of the Study Two participants' accounts of living with psychosis highlight how their energies were directed at preventing a reoccurrence of the illness. A number described medical interventions and ongoing psychosocial supports as crucial in this process. This included medication that helped to alleviate the symptoms of the illness. However, participants also demonstrated that illness recovery was not merely an absence of the symptoms of psychosis. A number of participants expressed aspirations for living fulfilling lives in their communities. They highlighted that the course of recovery required re-using and further developing skills and competencies both to cope with the illness and to establish fulfilling social and community roles. These aspirations suggest that medical and community support services need to collaborate so that consumers are provided with integrated and holistic care and support. Services that create pathways to connect consumers with education and employment opportunities, stable accommodation, family, and social and community networks are pivotal in supporting psychological and social reintegration. Moreover, when all services intentionally build consumers' internal psychological resources during all phases of the recovery process, there is an increased likelihood that consumers will stay well for longer and achieve their aspirations for the best possible life outcomes.

#### **8.2.3** Contribution Two: Service Development Initiatives

There are a number of impediments that need to be considered if services are to respond more effectively to CTA and utilise resilience as a recovery tool. As I previously noted, the most challenging systems issue is the limited capacity of services to include CTA as part of targeted, holistic intervention and care. This can partly be attributed to the clinical imperatives of managing psychosis symptomology. Consequently factors such as CTA and resilience that potentially accelerate recovery may be overlooked or not be considered a high priority for intervention and support. Alternatively, as questions have been raised about the reliability of traumatic recollections in psychosis populations and their potential to compound the symptoms of psychosis, CTA may intentionally remain unaddressed (Seligman & Csikszentmihalyi, 2000). Furthermore, in my experience as a mental health clinician, services in disadvantaged communities are often consumer rich and resource poor. This can potentially limit service capacity to move beyond illness symptomology and management to encompass more holistic, strengths-based clinical approaches.

The minimal clinical acknowledgement of CTA and the underutilisation of resilience as a recovery mechanism can also be attributed to a knowledge gap within services about the effects of CTA and the potential of resilience to enhance psychosis recovery. Moreover, there is uncertainty in the practice field about the most effective treatment praxis for populations presenting with both psychosis and CTA. Although practice standards, programs and intervention strategies are well established for mental health disorders such as PTSD, borderline personality and anxiety disorders, there is less clinical guidance in how to identify and effectively manage CTA and develop resilience in people with a psychotic illness. This can be attributed to the limited evidence and knowledge base in the field of CTA, psychosis and resilience that impedes the development of therapeutic techniques and intervention programs. It also impedes the further development of

clinicians' skills to apply resilience-enhancing techniques in clinical, therapeutic and case management processes. In addition, the effectiveness of clinical intervention and support is contingent upon the comprehensive assessment of the internal and external factors that contribute to an individual's illness and recovery. These assessments are the foundation of targeted, responsive clinical mental health practice. However, as I have discussed, multilayered clinical assessments that include an appraisal of resilience are challenging due to the suitability of the resilience measures currently available for this population.

The constraints confronting services and clinicians are to be expected given the limited evidence and conceptual base in the field. To address these impediments, further research that establishes the connections between CTA and resilience in psychosis populations is required. As I have stated, identifying the aspects of resilience that are critical for recovery and how these are developed in people who have experienced CTA and live with psychosis has direct implications for clinical practice. In addition clinical tools and resilience-focused clinical practice paradigms based on evidence about the development of resilience in people with a mental illness need to be developed. This requires well-resourced collaborative partnerships between researchers and clinicians. These have the potential to promote better research dissemination and utilisation within services while also informing course content and training for the preparation of practitioners in medicine, nursing, psychology and social work disciplines.

Although further research that explores the interrelationships between resilience, CTA and psychosis is needed, a substantial body of research about psychosis, CTA, trauma and post-traumatic growth currently exists. This provides a rich knowledge base for ongoing professional training of mental health practitioners that would deepen understandings about the prevalence and psychological impact of trauma and/or adversity. This proposal is

based on the assumption that when clinicians have the opportunity for ongoing professional learning there is an increased likelihood they will continuously improve the effectiveness of their assessment, therapeutic and case management skills and practices. This, in turn, means that consumers are likely to have access to quality evidence-based services attuned to their holistic health and psychosocial needs. However ongoing professional training needs to be delivered in ways that meet the diverse roles and needs of working in complex systems. For example, Courtios and Gold (2009) and Alvarez, Roura et al. (2011) suggest that training for practitioners needs to be delivered in both disciplinespecific and cross-disciplinary forums. This supports the concept of integrated mental health services and multidisciplinary practice required to support consumers in all phases of their recovery. It emphasises that training can be structured and facilitated in a variety of ways including practitioner research and joint practice development. This kind of training does not rely on the transference of knowledge by experts in particular fields. Rather it is research informed and involves professional interaction and the joint development of practice. However, in proposing these initiatives I acknowledge that policy makers sometimes do not recognise that mental health is an evolving field. Therefore resources need to be devoted to the provision of continuing professional learning opportunities for the mental health workforce.

There are also challenging legal and statutory issues that confront mental health services when working with psychosis/CTA populations. The legal obligation of reporting some categories of CTA is complex for both consumers and services. Although the reporting of historical CTA event(s) in adults is not statutorily required, information pertaining to these events can continue to have criminal relevance. The statutory requirements regarding CTA therefore require mental health services to implement strict legal and clinical practice protocols to ensure due diligence is followed when consumers report CTA. However, from

a consumer perspective, disclosing past CTA events can present significant personal difficulties that make consumers reluctant to engage in any clinical intervention relating to CTA. Moreover, if mandatory CTA reports are made against the wishes of consumers, clinical treatment can be significantly compromised. This suggests that the statutory acknowledgement of CTA within clinical settings requires policy and clinical clarity to ensure the best health and psychological outcomes for consumers. This is particularly important given that people with a history of CTA, particularly sexual abuse, rarely disclose or report the abuse (Courtois & Gold, 2009).

The above service challenges highlight that developing resilience in people with CTA and psychosis is highly complex. These challenges can be viewed as insurmountable obstacles to addressing CTA and implementing resilience-focused clinical practice. However, I suggest that it is not beyond the scope of mental health services, government and health jurisdictions to address these issues. A clear, consistent public health policy mandate is required to address these clinical and service delivery challenges. Practice mandates with a specific clinical focus on evidence-based interventions and care for psychosis/CTA populations may provide the imperative to address these constraints. However, interventions and care need to be based on best practice and informed by current research. Moreover, consistency in the development and implementation of federal and state health policy is required for both government and non-government sectors. The consumers of mental health services are integral to the development and evaluation of best practice. Their voices and perspectives need to form a significant part of the evidence collected regarding whether services are meeting their immediate and ongoing psychosocial, physical and recovery needs.

# 8.2.4 Contribution Three: Addressing Social Disadvantage

Evidence from the mental health field indicates that people with psychosis predominantly live in poverty and experience social disadvantage (Read & Fraser 1998, Hammersley, Read et al. 2008). The findings from Study One are consistent with these findings. There is also consensus in the mental health field that the consequences of poverty and mental illness, such as social isolation, poor health and low levels of employment, are linked (Croudace, Kayne et al. 2000, Boydell, Van Os et al. 2004, Morgan, Waterreus et al. 2012, Ramsay, Stewart et al. 2012). However, unique to this research is the evidence from Study Two indicating that, despite living with poverty and disadvantage, the majority of participants continued to display resilience. This included aspirations for a fulfilling and contributing life. However, as participants in this PhD research described, these aspirations are difficult to achieve when there are barriers such as social isolation, limited financial resources and poor employment opportunities. For some, stigma was also perceived as a significant impediment to establishing meaningful social and vocational roles in the community.

The health and psychosocial perspective that frames this PhD research has the potential to contribute to discussions about mental health practice in disadvantaged communities. It informs health and social policy by raising questions about the capacity of mental health services in disadvantaged communities to fulfil their mandate of being recovery oriented, strengths focused and individually targeted. As I have described, services within the research catchment area studied in this research catered for large numbers of consumers with complex needs. The South Australian SHIP data confirmed evidence from other research indicating that people with psychosis experience greater levels of poverty, economic isolation and poor physical health outcomes than the general population. Poverty, social isolation and stigma in turn can impede the recovery process (Saraceno & Barbui, 1997).

As I discussed in Chapter 7, disadvantaged communities such as the SHIP catchment where mental health populations are most likely to be located are often socially and economically complex (Onken, Dumont et al. 2002, Perese 2007). They may be characterised by poor social cohesion (Cattell, 2001), limited access to employment (Forrest & Kearns, 2001), diminished social mobility (Weich & Lewis, 1998), low productivity (Fox, 1990), and restricted access to education and health care opportunities (McDaid, Jenkins et al. 2011). The low SES of the northern region of Adelaide, South Australia where the SHIP research cohort is concentrated reflects these characteristics (Lorant, Deliege et al. 2003).

The South Australian SHIP data, together with a substantial body of research that highlights the effects of poverty and disadvantage on people with a mental illness, points to the need to consider how mental health is managed and resourced in disadvantaged communities. Service delivery constraints mean that individuals with a mental illness in these communities often have more limited access to over-utilised services, programs and community resources linked to social and health pathways to recovery. I suggest that the provision of holistic care and effective, targeted clinical interventions for people with psychosis and CTA demands that well-resourced, acute care services work in concert with equally well-resourced community networks. Such a system requires a multi-skilled workforce that works collaboratively across the public, private, non-government and not-for-profit sectors.

Developing these capacities requires the provision of resources, professional development and ongoing training of mental health professionals so that they are able to provide effective, evidence-based practice for highly complex populations. It requires the development of a balanced and coordinated mental health system that has the capacity to provide integrated psychiatric, medical and community-based interventions and support. Fundamental to this is the development of pathways that connect people with education, employment opportunities, families, and social and community networks. As I have stated, this does not negate the need for acute psychiatric services for people with a mental illness. Rather it challenges policy makers and services to look beyond this aspect of care to consider the principles that underlie current practice paradigms and review their effectiveness. This is essential when mental health services are operating in complex and changing political environments that demand service accountability and competition for scant resources. However, it is clear that redressing the poverty and disadvantages experienced by people with psychosis requires increased access to existing services. It also requires the expansion of new initiatives that provide acute intervention and strong community-based support. This task requires a commitment and action by governments to improve existing mental health and community-based services for people with a mental illness.

# 8.2.5 Contribution Four: Psychological Resilience Measures for Psychosis

# **Populations**

The findings from this research suggest that the assessment of resilience is an essential element in the planning of consumers' pathways to recovery. Mental health assessments provide the clinical information required for the development of individualised, tailored interventions and case management plans for treatment and care. The assessment of resilience as a component of psychosocial assessments of consumers would provide clinicians with more comprehensive information about the interrelated health and psychosocial factors that influence functioning. It would enable clinicians to work intentionally with service users to develop the internal resources (such as resilience) needed for recovery as well as the external resources and supports (such as employment)

that enable recovery and independence. It is particularly crucial in the treatment of individuals with psychosis who live in disadvantaged communities. As I have discussed, poverty and associated disadvantage impose increased demands on an individual's psychological capabilities. Therefore the assessment of resilience, as one of a range of interrelated psychological and environmental resources required to facilitate recovery, is crucial in planning treatment and care for individuals with psychosis who live in disadvantaged communities.

However, as evidenced when using the Resilience Scale, there are difficulties confronting researchers and clinicians in measuring resilience in psychosis populations. Most significantly, the measurement of resilience in these populations requires an accredited, time-efficient, specifically tailored measure. In view of the limitations of the Resilience Scale discussed in Chapter 6, I suggest that further research is required to develop a resilience measure that more accurately predicts the ability to psychologically cope with adversity in people with psychosis. Other resilience measures similarly require more extensive testing and evaluation with larger research samples, particularly mental health populations.

This research has therefore highlighted that an opportunity exists for the development of a specific resilience measure for mental health populations. I suggest exploring available resilience measures and adapting them for use with specific populations as one potential pathway. In addition to its practice implications, an accredited and validated resilience measure for use with specific populations would inform and strengthen the empirical base that currently underpins resilience research and theory.

However, although there are limitations in the measures that can be used to assess resilience in this population, I suggest that a general assessment of consumers' resilience can take place using the Resilience Scale or other measures such as self-reports and questionnaires. In this PhD research there was correlation between participants' self-assessments of resilience and their results on the Resilience Scale. I suggest that the critical part of an assessment process is the discussion of the assessment information with the consumer. This means that the consumer validates the results of the assessment and participants in developing an accurate clinical picture that is the basis of their recovery plans.

#### 8.2.6 Contribution Five: Further Research

This PhD research has established that a more substantial evidence and knowledge base about the complex interrelationships between CTA, resilience and psychosis needs to be established. This has direct implications for how mental health services establish their core clinical focus and work with consumers. Therefore I suggest that the empirical knowledge generated by research must be the kind that can be disseminated to mental health clinicians and be utilised to inform policy and practice. In this regard, services also have a responsibility to establish the working conditions that enable clinicians to engage with research as part of continuous job-embedded training. This should also include practitioner-led research opportunities. If this were to occur, opportunities would be created for researchers, policy makers and mental health practitioners jointly to address the impediments that hinder the provision of resilience-focused, evidenced-based care for people with psychosis and CTA.

This PhD research has highlighted that resilience is manifested in a variety of ways in people with psychosis. However, further research is required to identify the psychological competencies and dispositions that are evident in people with psychosis (e.g. self-reliance,

optimism, problem-solving skills) and identify those that are most pivotal in recovery. In view of the small scale of this research, further investigation in more diverse settings and with more diverse population groups is required to verify and expand on these findings. The question of why some people with the experience of CTA (e.g. the Study Two cohort) develop resilience while others become psychologically damaged (as evidenced by the wider research field) has not yet been clearly established.

Studies that examine CTA as a precursor to the development of resilience in people with psychosis have not been widely conducted in research or clinical practice. This PhD research therefore is one of the first of its kind to attempt to understand the relationships between CTA, resilience and psychosis recovery. What is clear from the findings is that there are a number of complex interrelated processes that contribute to the development of resilience, including CTA and psychosis events themselves. Further research is therefore required to identify the range of external and internal factors that contribute to the development of resilience in people with a mental illness. Unravelling the complex, interacting factors that contribute to the development of resilience in people with CTA and psychosis will provide important insights into the psychosocial functioning of individuals and their potential for recovery. This has great significance for clinical treatment and case management.

As I noted previously, analysis of the South Australian SHIP data revealed a high number of participants who self-reported CTA experiences. The high prevalence of CTA in this psychosis cohort has also been confirmed in other psychosis populations. However, the questions raised in this PhD research suggest that further investigations into the developmental trajectories associated with CTA and psychosis is required. There is a need to establish the significance of resilience as one of a number of possible factors that may

disrupt the link between CTA and poor psychological and health outcomes. How psychosis populations psychologically manage the intersections between these factors, including the need to maintain illness recovery, is a complex question that can only be addressed through comprehensive long-term research.

In addition, information is needed to evaluate the effectiveness of current interventions and care protocols provided by clinical mental health services in relation to CTA and psychological resilience. In the current mental health system evidence about the utilisation rates of CTA-specific services that support mental health populations is limited. Furthermore, it is difficult to identify services that view their practices through a resilience-enhancing perspective. This includes evidence about whether this approach makes a difference to the health outcomes of consumers. Nonetheless, this kind of research is unlikely to occur unless there is a broad and coordinated focus on research and evaluation in mental health. This needs to provide evidence about the quality of care and support across all service sectors. Evidence from consumers regarding their experience(s) of clinical and non-clinical mental health services is central to service evaluation at both a micro and macro level. From the perspective of this research, this includes the extent to which consumers are involved in identifying their own capabilities and paths to illness recovery. As I stated previously, this is contingent on new policy agendas and mental health becoming a much higher priority for government policy and service planning.

However, it is important to acknowledge that in the field of mental health this PhD research is small and modest in scale. Broader research that informs mental health policy and practice needs to be tied to the development of public policy. It needs to be funded by governments with a commitment to whole-system reform and innovation. In making recommendations for future research I understand that, regardless of quality, its findings

and recommendations may not make their way into clinical practice. The reasons for this disconnect between research and practice is complex. As I have highlighted, these may include a lack of ongoing training for practitioners, few opportunities for clinicians to be involved in research and public policy development, as well as a lack of consensus about what constitutes an effective national mental health system. Until strategies are found to increase the communication between researchers and practitioners, this disconnect will continue, with a consequent loss of opportunities to develop the most effective resilience-focused care and treatment.

### 8.3 Conclusion: Finding and Contributions

This research has expanded current understandings about psychological resilience. I have identified the prevalence of CTA and psychological resilience in a regionally representative psychosis population. I have identified CTA as a possible determinant of resilience in some individuals. I also identified resilience as a factor that potentially enhances recovery from psychosis. However, further empirical investigation is required to verify and expand on these findings. Additional research needs to establish:

- the prevalence of CTA within psychosis populations across broader demographic jurisdictions;
- 2. the concentration of CTA within psychosis populations across all social and economic jurisdictions and demographics;
- 3. the measurement of psychosis consumers' levels of resilience and their capacity to psychologically manage and cope in the context of recovery from their illness;
- 4. the specific skills and dispositions of resilience that are most significant in recovery from psychosis;
- 5. clinical strategies to incorporate psychological resilience into the praxis of mental health clinicians working with this cohort;

 whether psychosis populations perceive that a focus on psychological resilience as part of clinical intervention and support improves their health and/or social outcomes.

The experiences and insights of participants in this research highlighted the complex health and social challenges of the lived experience of psychosis. However, in this research I primarily investigated the relationship between CTA and psychological resilience in a psychosis sample. I did not seek to establish whether CTA was a causal factor in the development of psychosis. However, I suggest that a better understanding of the significance of the causal links between CTA and psychosis would provide further insight into the development of resilience and its manifestation in this population.

In this research I have examined the above topics from a social and health perspective. I have confirmed the links that have been established in the wider research field between psychosis, poverty and social disadvantage. I propose that the combination of psychosis and social disadvantage can create additional stressors for people with complex mental health needs and trauma histories. These stressors may potentially diminish resilience and impede illness recovery. I have provided insight into the significant challenges that confront services in disadvantaged communities attending to the range of complex factors created by social disadvantage and mental illness. This raises questions about the capacity of services in these locations to promote individualised clinical support that builds resilience and addresses CTA. The wide social and health perspective that frames this research highlights that policy, praxis and resource initiatives are required to address the disadvantages created by psychosis. I suggest that this requires mental health reform and additional funding for the development of a well-resourced, nationwide, integrated mental health service system. Such a system would provide individuals in disadvantaged

communities with full access to services, programs and community resources linked to social and health pathways to recovery. Moreover, services would be informed by current evidence about mental illness and allow linked data to measure service quality and consumer outcomes. This PhD research contributes some of the evidence supporting calls for that reform effort.

Through this research I have also sought to contribute to professional dialogue about the effectiveness of current clinical practice and policy. I have offered recommendations to make services more responsive to the needs of the unique consumer group who made up the research population. Hence, I have raised some of the factors that prevent services adopting resilience-focused approaches. These include the limited applicability of resilience assessment tools and clinical practice frameworks for psychosis populations. I have made observations about the capacity of under-resourced services to provide opportunities for ongoing, on-the-job clinical training for clinicians. I suggest that this may compound the lack of awareness of the significance of CTA as a potentially resilience-forming event and illness recovery tool. In the final chapter I summarise these recommendations.

# Chapter 9

#### **Conclusion**

#### 9.1 Introduction

This chapter summarises the findings of this PhD research and its contribution to enhancing knowledge about psychosis, CTA and resilience. I review the outcomes from the research, including a discussion of its strengths and limitations. I also include a summary of the implications of the research for clinical mental health praxis, including recommendations for future research about resilience in people with psychosis and CTA.

# 9.2 Significance and Contributions of the Research Findings

This PhD research confirms the findings from a large body of literature demonstrating that psychosis and/or CTA are significant life events. The research has drawn attention to the resilience capacities of people with psychosis and the experience(s) of CTA. To clarify, a significant finding of the research is that the resilience of the majority of participants was well beyond what might be hypothesised given their CTA experiences(s) and from living with psychosis. In some instances, CTA was one of the defining factors in the development of resilience and was a positive influence on the recovery from psychosis.

Evidence that CTA may have a defining influence on resilience highlights the importance of acknowledging individuals' experiences of CTA in the health and psychological treatment of clinical mental health consumers. My recommendations for the improvement of clinical mental health practice are based on participants' accounts of how they developed resilience in the process of coping with CTA. The contributions of this research are strengthened by participants' deep understandings of their skills, capabilities and dispositions that constitute their understandings of resilience and how they applied these traits in their recovery. This evidence has led to the recommendation that resilience should

be considered as an individual asset that can be intentionally developed in a clinical mental health context to enhance the illness recovery of the consumer.

By illustrating that individuals with a history of CTA and with a diagnosis of a psychotic illness can display considerable resilience, the research thus draws attention to the ways that researchers and clinicians may psychologically construct people with a mental illness. I suggest that if individuals with the experience(s) of CTA and psychosis are positioned solely in relation to their symptomology, they can only be viewed solely in relation to their psychological and social deficits. This conceptualisation can negate the central role that psychological assets such as resilience play in individuals' capacity to recover from illnesses such as psychosis. By demonstrating that the development of resilience can be an outcome of CTA, this research emphasises that individuals with a CTA history and a lifelong mental illness have the capacity to adjust and grow in response to significant life challenges. This view is also fundamental to the philosophy that underlies recovery-based mental health services.

Although this research has illustrated that the development of resilience may be at the core of psychological growth following CTA, it also highlights that the experience of CTA can also be highly distressing. I want to emphasise that resilience development following trauma and/or adversity does not negate the highly distressing nature of the individual experience(s) of CTA. Furthermore, as research in the resilience field has demonstrated, the development of resilience is not solely contingent on the experience(s) of trauma and/or adversity. Many individuals develop resilience in safe, psychosocially enabling environments that enable them to develop the psychological abilities required to manage stress and adversity in their lives.

Finally, findings from this PhD research also demonstrate that the lives of people with psychosis are often characterised by poverty, social isolation, poor health and low levels of employment. These factors underline the complex factors that can adversely affect the lives of people with psychosis. I propose that poverty and social disadvantage potentially impede the recovery process as they can diminish an individual's internal psychological resources, including resilience. Moreover, my research findings suggest that these factors often limit access to external services and programs that support recovery, particularly in communities characterised by social disadvantage.

### 9.3 Additional Questions Raised by the Research Findings and Contributions

Further questions about the topics in this research emerged in the process of conducting this study. As I have discussed, a significant body of research about the development and manifestations of resilience in the domains of education, psychology, psychiatry and health service has been established. Although consensus about the importance and manifestation of resilience has emerged across these domains, additional questions remain about the complex interactions of the traits and skills that constitute resilience. Consequently, conjecture about the internal psychological factors and processes that are most significant in enhancing resilience are still evident in the literature.

Similarly, there are diverse views about the environmental factors that are most significant in the complex interplay of factors that contribute to the development of resilience in the face of CTA. In regards to people with a psychotic illness, questions remain about the characteristics of resilience (e.g. problem solving, optimism, identity and self-acceptance) that most enhance recovery from CTA and psychosis. I propose that a more conclusive evidence and theoretical base is required about the development and role of resilience in psychosocial functioning in people with a mental illness. This is a necessary precursor to

the design of interventions to enhance resilience in clinical mental health settings (Shiner and Masten 2012).

#### 9.4 The Limitations of the Research

The limitations inherent in the research have been specifically discussed in relation to aspects of each study through this dissertation (see sections 4.7.1, 5.9, 6.7 and 7.7). However, several limitations as they apply PhD overall to this research need to be highlighted. For example, aspects of this PhD research relied on retrospective reports of participants' CTA experience(s). Consequently, there is a possibility that participants' illnesses may have influenced their recall of the CTA and other events in their lives. Elevated psychosis symptomology may have also restricted the capacity of some participants' to reconstruct and interpret their experience(s) of CTA and its effects upon their ability to manage and recover from psychosis. Much of the existing research investigating the relationship between CTA and psychosis uses retrospective participant reports. A range of instruments have been developed to investigate the relationship between CTA and other disorders (e.g. depression), which employ a number of strategies to overcome the potential problem of recall bias (e.g. the use of a life history calendar, use of multiple sources of information, assurances of confidentiality). However, Fisher, Craig et al. (2009) suggest that problems of recall have not been effectively addressed in major studies of CTA conducted to date. They assert that current research uses relatively crude measures of traumatic and/or adverse experiences that increase the risk of systematic information bias. Therefore, the self-reports of participants' CTA experiences during the Study Two face-to-face interviews need to be considered with some caution. Supplementary measures that assessed participants' CTA experiences may have strengthened the data collected from the face-to-face interviews. This would have provided additional reliability regarding participants' self-reports and further scope for analysis and interpretation.

Additionally, the influence of external health and psychosocial influences on the development of resilience was not investigated in this PhD research. These include family circumstances and socioeconomic status as well as post-trauma counselling. As I previously described, I asked participants in Study Two whether they had received any psychological intervention or support regarding the experience(s) of CTA. However, I did not ask them to describe the kind of counselling they had received. It was also unclear whether participants had been provided with counselling services at the time of the CTA event(s), whether counselling had been organised on their behalf (e.g. by a family member, mental health clinician or GP), or whether they had participated in counselling because of these efforts. Thus, a more in-depth exploration of participants' views about the kinds of services and interventions that best support recovery from CTA would strengthen the research recommendations regarding clinical treatment.

# 9.5 The Strengths of the Research

Although integrating quantitative and qualitative studies presented some challenges, this mixed methodology proved to be an effective technique for investigating the complex ideas of the research. The quantitative data collected from Study Two and the statistical analysis applied to the large SHIP data set in Study One established the demographic profile of a psychosis cohort living in a highly disadvantaged community. I consequently identified the outcomes of psychosis and established the social and health context that framed the qualitative investigation into resilience and CTA. This evidence highlights the complex interplay of factors that can contribute to the lived experience of psychosis. Furthermore, the finding that psychosis has a severe health, psychological and social impact on individuals that often leads to disadvantage and disability has been confirmed in an extensive body of research in the field (Dvir, Denietolis et al. 2013).

Consequently, my analysis of the findings from the qualitative and quantitative studies has led me to make a number of evidence-based recommendations about consumer care and recovery practice. Fundamental to these is the proposition that clinical mental health practice needs to be extended beyond a focus on symptomology to include consideration of the complex psychological, social and experiential life factors (e.g. CTA) that can contribute to illness recovery. The evidence from this PhD research indicates that consumer care needs to enhance an individual's internal psychological resources (such as resilience) as the drivers for recovery, as well as the environmental resources (such as housing, education and employment support) that address the challenges created by external factors such as poverty and disadvantage.

The sample of Study Two participants extracted from the SHIP cohort was regionally representative and culturally diverse and this has ensured some transferability of the Study Two results. Participants' participation in face-to-face discussions regarding their personal experiences and insights ensured that the Study Two sample size was sufficient to reach theme saturation. These accounts allowed for the exploration of participants' personal experiences that are distinct from traditional mainstream narratives (Richards & Morse, 2002). This gave voice to more nuanced accounts that could not have been fully explored by utilising a quantitative research approach.

The interpretive lens of Study Two has provided insight into participants' histories, the impact of psychosis and their ongoing life challenges. It captured participants' understandings about resilience and its effect on many aspects of their lives. This provided a richer understanding of how resilience is manifest in the research population. Participants' personal stories led to the question whether this often underrepresented research cohort receives the social support, health policy focus and comprehensive mental

health services they require to live a full life in their communities. Finally, the thematic analysis and maintenance of an audit trail enhanced transparency, reflexivity and a clear exposition of the methods of data collection and analysis. In conclusion, the combination of interpretive qualitative analysis with the quantitative data analysis of SHIP provided scope for a deeper understanding of how resilience can affect many domains of life, including psychological and social functioning.

# 9.6 Concluding Statement

Meaningful findings and recommendations for future research and the development of the clinical mental health practice field have arisen from this PhD research. This includes the recommendation that mental health systems philosophy and practice should recognise and intentionally develop the resilience seemingly inherent in psychosis/CTA populations. Related to this recommendation are my suggestions for improving mental health clinicians' understandings of resilience and its centrality to recovery in psychosis. In regards to services that define the consumer experience, I have identified several mental health praxis areas that require further investigation. This includes the need for more longitudinal research of mental health and psychosis management service effectiveness in CTA-specific psychosis populations in South Australia. Determining which services address CTA and why is a first step to identifying the capacity of mental health treatment services that consider the topic of resilience in people with a psychotic illness. An important aspect of service evaluation is the involvement of consumers in identifying their capabilities and in the decision making that helps to define the outcomes and paths to illness recovery.

This PhD research has highlighted that there are a number of impediments to the implementation of resilience-focused clinical practice. One of these is that few assessments of resilience or practice frameworks for mental health clinicians currently exist to assist in the identification and development of resilience in psychosis populations. This is also a

potential area for future research and practice innovation. However, I understand that the findings and recommendations that have emerged from this PhD research are based on a small and modest study. It is clear that further empirical and conceptual research is required to verify its findings. Common understandings based on further evidence from different contexts will have the legitimacy required to influence the parameters of policy and practice. This in turn will have the potential to change the lives of people with psychosis in profound and enduring ways.

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## **Appendices**

## Appendix 1

## **Participant Contact Letter- Pilot Study**



Northern Adelaide LHN Inc Lyell McEwin Hospital Haydown Road ELIZABETH VALE SA 5112

(Insert date)	Tel 0402 638 098 Fax 08 8222 2865
	shaun.sweeney@adelaide.edu.au

Dear....,

In the last 18 months, you participated in the Survey of High Impact Psychosis (SHIP) study and you were interviewed by one of our researchers. During the SHIP interview, you identified childhood trauma as a significant event in your life. We would like to offer you the opportunity to participate in another research project looking at the impact that the experience of childhood trauma has had upon your life.

This research will be interviewing a number of people in your community and is designed to find out how childhood trauma impacted on resilience. If you participate, you will be reimbursed \$30 for your time and travel expenses. The interview will be about 1 hour in length. Participation in this interview is entirely voluntary.

I have enclosed an information sheet and consent form that gives more details about what is involved should you agree to take part. I will call you within the next 7 days to explain the interview to you, answer any questions you may have, and find out whether you would be interested in taking part. My telephone number is at the bottom of this letter if you would prefer to call me. However, if you do not want to be involved please sign and return this letter in the reply paid envelope.

Yours sincerely,

Principal Researcher- Shaun Sweeney Address: University of Adelaide, Discipline of Psychiatry Telephone no: XXXX XXX XXX

I do not want to take part in the interview.

Signature

Name

### **Participant Information Sheet-Pilot Study**



#### THE NORTHERN ADELAIDE LOCAL HEALTH NETWORK

#### PARTICIPANT INFORMATION SHEET

Title: Pilot study- "Investigating the impact of childhood trauma on the development of resilience and the long-term psychosocial status of people diagnosed with a psychotic

#### Protocol Number: 2011143

#### INVITATION TO PARTICIPATE

We invite you to participate in a research project which we believe is of potential importance. However, before you decide whether or not you wish to participate, we need to be sure that you understand

#### why we are doing it, and

#### what it would involve if you agreed.

We are therefore providing you with the following information. Please read it carefully and be sure to ask any questions you have.

The person conducting the research will be happy to discuss it with you and answer any questions that you may have.

You are also free to discuss it with outsiders if you wish. (le family, friends and / or your local Doctor)

#### You do not have to make an immediate decision.

Your participation is purely voluntary. Should you agree to enter the trial, you may change your mind and withdraw at any stage.

#### PARTICIPATION IS VOLUNTARY

Participation in any research project is voluntary. If you do not wish to take part, you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage without providing a reason.

Your decision to take part, not to take part or to withdraw will not affect your routine treatment, your relationship with those treating you, or your relationship with The Northern Adelaide Local Health Network.

#### **BACKGROUND TO THE STUDY**

#### What is the research about?

This a trial interview for a larger PhD research study. It is a face-to-face interview about the impact that childhood trauma has upon resilience. What we would like to know is how you are able to cope with bad events and if trauma in childhood made a difference to your ability to manage.

#### Why is the research being done?

This is a trial of a face-to-face interview about trauma and resilience with people who have been diagnosed with a psychotic illness. This is a test of a resilience interview and some additional questionaries that will be used in a larger PhD research project in 2012-13.

Patient Information Sheet and Consent Title: Pilot Study- Childhood Trauma and Resilience Version 02 dated 28/11/2011

Page 1 of 4

#### Who is sponsoring it

 This interview is part of a larger PhD research project sponsored by Adelaide University and the Northern Mental Health Directorate.

#### How and why have I been chosen as a possible participant in the research?

You participated in the Survey of High Impact Psychosis (SHIP) research project in 2010
and have been selected from that group of participants from that study who identified
trauma as an event in your childhood. You also gave permission for us to re-contact you
again to see if you would like to participate in other research.

#### How many other people have been asked to consider participating?

 A total of 10 interviews will be completed in this trial part of the larger PhD research project.

#### PROCEDURES AND TREATMENT

## Will I have to come back to the clinic more often or remain in hospital for longer than would normally be the case?

This is a single, one off, face-to-face interview. Upon completion of the interview you
won't be required to participate in any additional interviews related to this research.

#### What will I be asked to do at each visit?

You will be asked a series of questions about resilience, trauma and psychosis and
if/how it has impacted upon your life. You will also be asked for complete a number of
very short questionnaires asking you about resilience.

#### How long will my participation in the study last?

. The one-off interview will be no longer than 60 minutes in length.

# What procedures will I be asked to submit to including exposure to radiation and what will be the likely effects?

 You will not be required to do anything other than participate in the interview at a mental health site in the northern suburbs of Adelaide.

# What treatment will I get if I do take part? Will this be different from the treatment I would get otherwise? If so, how and in what ways?

This is a face-to-face interview only. You won't be required to discuss any treatments
from mental health services and this interview will not impact on your current treatments.

# Will the decisions about my treatment be made by my usual doctor or by someone else?

NA

# Are there any factors, which would exclude me from participating, like pre-existing illness, the possibility of becoming pregnant or other drugs being taken?

· Should you be unwell in anyway you will not be eligible to participate in the interview.

## WHAT WILL HAPPEN TO THE INFORMATION COLLECTED?

#### How will my confidentiality be protected – will the information and results be deidentified?

- · No identifying information about you will be used in any way.
- This interview is for the sole purpose of developing the face-to-face interview and trialling some resilience questionnaires.
- The recording of the interview will be used solely to determine the best interview questions for an upcoming PhD project.

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#### Will I be informed about the results of the study?

· No information collected during this trial interview will be available to participants.

### How long will my information be stored for?

 All information collected from the trial interviews will be kept in a secure location for 15 years.

### WHAT ARE MY RIGHTS?

If you become injured during this study, and your injury is a direct result of the effects of study procedures, The Northern Mental Health Directorate will provide reasonable medical treatment. Your participation in this study shall not affect any other right to compensation you may have under common law.

### How can I obtain more information?

Shaun Sweeney Principal Investigator The University of Adelaide, Discipline of Psychiatry Ph. 0402 638 098

### PAYMENT FOR PARTICIPATION

### Will I be paid for my participation?

· All participants in the trial interview will be paid \$25.00 for their participation.

### **BENEFITS OF THE RESEARCH**

# Is there any chance that the proposed research will be of benefit to me personally, or to future participants with the same condition?

The interview is unlikely to provide you with any direct benefit in the short term. However,
the information collected by the larger PhD study will provide information for services and
the public about the experience of childhood trauma and resilience for people diagnosed
with psychosis and this will ensure better outcomes for individuals with the lived
experience of mental illness.

### What medical care and follow up will I receive after the trial?

 Upon the completion of the interview you will be contacted by a principal investigator to check on your health and provide support if required.

### WHAT IF I HAVE A QUESTION ABOUT THE STUDY?

If you have any questions about the pilot study please contact-

Shaun Sweeney
Principal Investigator
The University of Adelaide, Discipline of Psychiatry
Ph. 0402 638 098
Email- shaun.sweeney@adelaide.edu.au

The Adelaide Health Service Human Research Ethics Committee has approved this study.

Should you wish to speak to a person not directly involved in the study in relation to:

- · matters concerning policies,
- · information about the conduct of the study
- · your rights as a participant, or
- · Should you wish to make a confidential complaint

you may contact The Executive Officer of this Committee, on (08) 8222 6841.

Patient Information Sheet and Consent
Title: Pilot Study- Childhood Trauma and Resilience
Version 020 dated 28/11/2011

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## **Participant Consent Form-Pilot Study**

### THE NORTHERN ADELAIDE LOCAL HEALTH NETWORK

### **CONSENT FORM**

#### Title

Pilot study- "Investigating the impact of childhood trauma on the development of resilience and the long-term psychosocial status of people diagnosed with a psychotic illness".

- I have read the information sheet, and I understand the reasons for this study. The research
  worker has explained the ways in which it will affect me. My questions have been answered to my
  satisfaction. My consent is given voluntarily.
- I understand that the purpose of this research project is to improve the quality of medical care, but
  my involvement may not be of benefit to me.
- · The details of the research project have been explained to me, including:
  - The expected time it will take
  - The nature of any procedures being performed, and the number of times they will be performed.
  - performed Any discomfort which I may experience
- I have been given the opportunity to have a member of family or a friend present while the project was explained to me.
- My identity will be kept confidential, and nothing will be published which could possibly reveal my identity.
- My involvement in the study will not affect my relationship with my medical advisers. I understand
  that I am able to withdraw from the study at any stage without having to give a reason, and that by
  withdrawing it will not affect my treatment at this hospital in the future.

PARTICIPANT SIGNATURE	 DAJE/
WITNESS:	 <b>DAJE</b> /
INVESTIGATOR:	DATE//

Patient Information Sheet and Consent Title: Pilot Study- Childhood Trauma and Resilience Version 02 dated 28/11/2011

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# **Appendix 2:**

## **Participant Consent Form- Main Study**



(Insert date)	Northern Adelaide LHN Inc Lyell McEwin Hospital Haydown Road ELIZABETH VALE SA 5112
Dear,  In the last 18 months, you participated in the Survey of	Tel 0402 638 098 Fax 08 8222 2865 shaun.sweeney@adelaide.edu.au High
Impact Psychosis (SHIP) study and you were interviewed b interview, you identified childhood trauma as a significant you the opportunity to participate in another research projec of childhood trauma has had upon your life.	y one of our researchers. During the SHIP event in your life. We would like to offer
This research will be interviewing a number of people in you how childhood trauma impacted on resilience. If you particitime and travel expenses. The interview will be about 1 hour entirely voluntary.	ipate, you will be reimbursed \$30 for your
I have enclosed an information sheet and consent form that should you agree to take part. I will call you within the ne answer any questions you may have, and find out whether y telephone number is at the bottom of this letter if you would want to be involved please sign and return this letter in the re-	ext 7 days to explain the interview to you, you would be interested in taking part. My prefer to call me. However, if you do not
Yours sincerely,	
Principal Researcher- Shaun Sweeney Address: University of Adelaide, Discipline of Psychiatry Tel phone no: XXXX XXX XXX	
I do not want to take part in the interview.	
Signature	
Name	

## **Participant Information Sheet-Pilot Study**



THE NORTHERN ADELAIDE LOCAL HEALTH NETWORK
Livel McEwin Hospital and Modbury Hospital

### PARTICIPANT INFORMATION SHEET

Title: PhD study- "Investigating the impact of childhood trauma on the development of resilience and the long-term psychosocial status of people diagnosed with a psychotic illness".

Protocol Number: 2012042

### INVITATION TO PARTICIPATE

We invite you to participate in a research project which we believe is of potential importance. However, before you decide whether or not you wish to participate, we need to be sure that you understand

### why we are doing it, and

### what it would involve if you agreed.

We are therefore providing you with the following information.

Please read it carefully and be sure to ask any questions you have.

The person conducting the research will be happy to discuss it with you and answer any questions that you may have.

You are also free to discuss it with outsiders if you wish. (i.e. family, friends, and / or your local Doctor)

#### You do not have to make an immediate decision.

Your participation is purely voluntary. Should you agree to enter the study, you may change your mind and withdraw at any stage.

## PARTICIPATION IS VOLUNTARY

Participation in any research project is voluntary. If you do not wish to take part, you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage without providing a reason.

Your decision to take part, not to take part or to withdraw will not affect your routine treatment, your relationship with those treating you, or your relationship with The Livell McEwin Hospital or the Modbury Hospital.

### **BACKGROUND TO THE STUDY**

### What is the research about?

This a PhD research study which involves a face-to-face interview about the impact that
childhood trauma has upon resilience. What we would like to know is how you are able to
cope with bad events and if trauma in childhood made a difference to your ability to
manage.

### Why is the research being done?

 This is a face-to-face interview about trauma and how resilience develops for people who have been diagnosed with a psychotic illness.

2012042 Participant Information Sheet and Consent Title: PhD Study- Childhood Trauma and Resilience Version 1.2 dated 04/04/2012

Page 1 of 4

### Who is sponsoring it

 This interview is part of a PhD research project sponsored by Adelaide University and the Northern Mental Health Directorate.

### How and why have I been chosen as a possible participant in the research?

You participated in the Survey of High Impact Psychosis (SHIP) research project in 2010
and have been selected from that group of participants from that study who identified
trauma as an event in your childhood. You also gave permission for us to re-contact you
to see if you would like to participate in other research.

### How many other people have been asked to consider participating?

· We hope to recruit 50 participants to this study.

#### PROCEDURES AND TREATMENT

# Will I have to come back to the clinic more often or remain in hospital for longer than would normally be the case?

This is a single, one off, face-to-face interview. Upon completion of the interview, you will
not be required to participate in any additional interviews related to this research.

### What will I be asked to do at each visit?

You will be asked a series of questions about resilience, trauma, psychosis, and if/how it
has influenced your life. You will also be asked to complete a very short questionnaire
asking you about resilience. The interview will be voice recorded.

### How long will my participation in the study last?

· The one-off interview will be no longer than 60 minutes in length.

# What procedures will I be asked to submit to including exposure to radiation and what will be the likely effects?

 You will not be required to do anything other than participate in the interview at a mental health site in the northern suburbs of Adelaide.

# What treatment will I get if I do take part? Will this be different from the treatment I would get otherwise? If so, how and in what ways?

 This is a face-to-face interview only. You will not be required to discuss any treatments from mental health services and this interview will not influence your current treatments.

# Are there any factors, which would exclude me from participating, like pre-existing illness, the possibility of becoming pregnant or other drugs being taken?

 Should you be physically or mentally unwell in anyway you will not be eligible to participate in the interview.

## WHAT WILL HAPPEN TO THE INFORMATION COLLECTED?

# How will my confidentiality be protected – will the information and results be deidentified?

- · No identifying information about you will be used in any way.
- This interview is for the sole purpose of researching how resilience affects your life.
- The voice recording of the interview will be used solely to help document the interview content and will not be publicly broadcast in any way.

### Will I be informed about the results of the study?

No information collected during this interview will be available to participants.

### How long will my information be stored for?

All information collected from the interviews will be kept in a secure location for 15 years.

2012042 Participant Information Sheet and Consent Title: PhD Study- Childhood Trauma and Resilience Version 1.2 dated 04/04/2012

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### WHAT ARE MY RIGHTS?

If you become injured during this study, and your injury is a direct result of the effects of study procedures, The Northern Mental Health Directorate will provide reasonable medical treatment. Your participation in this study shall not affect any other right to compensation you may have under common law.

#### How can I obtain more information?

Shaun Sweeney Principal Investigator The University of Adelaide, Discipline of Psychiatry Ph. 0402 638 098

### PAYMENT FOR PARTICIPATION

### Will I be paid for my participation?

All participants in the interview will be paid \$30.00 for their participation.

### **BENEFITS OF THE RESEARCH**

Is there any chance that the proposed research will be of benefit to me personally, or to future participants with the same condition?

 The interview is unlikely to provide you with any direct benefit in the short term. However, the information collected from this PhD study will provide information for services and the public about the experience of childhood trauma and resilience of people diagnosed with psychosis and this will ensure better outcomes for individuals with the lived experience of mental illness.

### What medical care and follow up will I receive after the trial?

 Upon the completion of the interview you will be contacted by a principal investigator to check on your health and provide support if required.

### WHAT IF I HAVE A QUESTION ABOUT THE STUDY?

If you have any questions about this study please contact-

Shaun Sweeney Principal Investigator The University of Adelaide, Discipline of Psychiatry Ph. 0402 638 098 Email- shaun.sweeney@adelaide.edu.au

The Human Research Ethics Committee (TQEH/LMH/MH) has approved this study.

Should you wish to speak to a person not directly involved in the study in relation to:

- · matters concerning policies,
- · information about the conduct of the study
- · your rights as a participant, or
- Should you wish to make a confidential complaint

you may contact The Executive Officer of this Committee, on (08) 8222 6841.

| 2012042 Participant Information Sheet and Consent Title: PhD Study- Childhood Trauma and Resilience Version 1.2 dated 04/04/2012

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# **Participant Consent Form- Pilot Study**

THE NORTHERN ADELAIDE LOCAL HEALTH NETWORK
Livell McEwin Hospital and Modbury Hospital

### **CONSENT FORM**

Title: 2012042

PhD study- "Investigating the impact of childhoo and the long-term psychosocial status of people of	
Protocol Number:	
I, the undersigned	
I have read the information sheet, and I understan worker has explained the ways in which it will affect satisfaction. My consent is given voluntarily.	
<ul> <li>I understand that the purpose of this research proj my involvement may not be of benefit to me.</li> </ul>	ect is to improve the quality of medical care, but
The details of the research project have been expl The expected time it will take The nature of any procedures being perforperformed Any discomfort which I may experience	<u>-</u>
I have been given the opportunity to have a memb was explained to me.	er of family or a friend present while the project
My identity will be kept confidential, and nothing w identity.	ill be published which could possibly reveal my
My involvement in the study will not affect my relat that I am able to withdraw from the study at any st withdrawing it will not affect my treatment at this he	age without having to give a reason, and that by
PARTICIPANT SIGNATURE	DATE//
WITNESS:	DATE//
INVESTIGATOR:	DATE//

2012042 Participant Information Sheet and Consent Title: PhD Study- Childhood Trauma and Resilience Version 1.2 dated 04/04/2012

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## **Appendix 3:**

## **Pilot Study Interview Schedule**

- 1. What's it like for you living with a psychotic illness?
- 2. How do you think the trauma you experienced in your childhood has affected your life?
- 3. How well do you think you have coped with your childhood traumatic experience?
- 4. In what ways do you think your experience of childhood trauma has impacted on your ability to cope with issues that arise on a daily basis?
- 5. What has helped you cope and not give up when you have had emotional or mental health difficulties?
- 6. Can you share a recent story about how you overcame a personal challenge in your life?
- 7. What communities are you connected to that help you to cope and deal with daily stress (e.g. friendship groups, sporting groups, social support networks)?
- 8. What communities would you like to be connected to and what stops you from participating?
- 9. If you could magically change something about your life what would it be?

## **Appendix 4:**

## **Main Study Interview Schedule**

## **Psychosis**

- 1. What is it like for you living with a psychotic illness?
- 2. How well do you think you have dealt with your psychosis?

### **Trauma**

- 3. How do you think the trauma you experienced in your childhood has affected you in your life?
- 4. Have you received any support or counselling to help you with dealing with your childhood trauma? What sort of support was it?
- 5. In what ways do you think your experience of childhood trauma has affected your ability to cope with issues that arise on a daily basis?
- 6. What has helped you cope and not give up when you have had emotional or mental health difficulties?
- 7. How well do you think you have coped with your childhood traumatic experience?
- 8. Can you share a recent story about how you overcame a personal challenge in your life?

### Resilience

- 9. What do you think resilience is? (Researcher Prompt- "An effective coping mechanism for when one is under emotional or psychological stress").
- 10. Do you think you are resilient? If yes, how do you think you became resilient?

## **Social Participation**

- 11. What groups are you connected to that help you to cope and deal with daily stress (for example: friendship groups, sporting groups, social support networks)?
- 12. What groups would you like to be connected to, and what do you think stops you from participating?

### Reflection

- 13. If you could magically change something about your life, what would it be?
- 14. Anything you would like to add?

## **Appendix 5:**

## **Resilience Measure: Resilience Scale**

Please read the following statements. To the right of each you will find seven numbers, ranging from "1" (Strongly Disagree) on the left to "7" (Strongly Agree) on the right. Circle the number which best indicates your feelings about that statement. For example, if you strongly disagree with a statement, circle "1". If you are neutral, circle "4", and if you strongly agree, circle "7", etc.

		Strongly Disagree		~ ·				ngly gree	
1. When I make plans, I follow through with them.		1	2	3	4	5	6	7	
2. I usually manage one way or another.		1	2	3	4	5	6	7	
3. I am able to depend on myself more than anyone else.		1	2	3	4	5	6	7	
4. Keeping interested in things is important to me.		1	2	3	4	5	6	7	
5. I can be on my own if I have to.		1	2	3	4	5	6	7	
6. I feel proud that I have accomplished things in life.		1	2	3	4	5	6	7	
7. I usually take things in stride.		1	2	3	4	5	6	7	
8. I am friends with myself.		1	2	3	4	5	6	7	
9. I feel that I can handle many things at a time.		1	2	3	4	5	6	7	
10. I am determined.		1	2	3	4	5	6	7	
11. I seldom wonder what the point of it all is.		1	2	3	4	5	6	7	
12. I take things one day at a time.		1	2	3	4	5	6	7	
13. I can get through difficult times because I've experienced difficulty before.		1	2	3	4	5	6	7	
14. I have self-discipline.		1	2	3	4	5	6	7	
15. I keep interested in things.		1	2	3	4	5	6	7	
16. I can usually find something to laugh about.		1	2	3	4	5	6	7	
17. My belief in myself gets me through hard times.		1	2	3	4	5	6	7	
18. In an emergency, I'm someone people can generally rely o	n.	1	2	3	4	5	6	7	
19. I can usually look at a situation in a number of ways.		1	2	3	4	5	6	7	
20. Sometimes I make myself do things whether I want to or r	ot.	1	2	3	4	5	6	7	
21. My life has meaning.		1	2	3	4	5	6	7	
22. I do not dwell on things that I can't do anything about.		1	2	3	4	5	6	7	
23. When I'm in a difficult situation, I can usually find my wa of it.	y out	1	2	3	4	5	6	7	
24. I have enough energy to do what I have to do.		1	2	3	4	5	6	7	
25. It's okay if there are people who don't like me.		1	2	3	4	5	6	7	
26. I am resilient.		1	2	3	4	5	6	7	

# **Appendix 6:**

# Resilience Measure: The Ego Resiliency Scale

		Does not apply at all	Applies slightly, if at all	Applies somewhat 3	Applies very strongly
1	I am generous with my friends	1	2	3	4
2	I quickly get over and recover from being startled	1	2	3	4
3	I enjoy dealing with new and unusual situations	1	2	3	4
4	I usually succeed in making a favorable impression on people	1	2	3	4
5	I enjoy trying new foods I have never tasted before	1	2	3	4
6	I am regarded as a very energetic person	1	2	3	4
7	I like different paths to familiar places	1	2	3	4
8	I am more curious than most people	1	2	3	4
9	Most of the people I meet are likeable	1	2	3	4
10	I usually think carefully about something before acting	1	2	3	4
11	I like to do new and different things	1	2	3	4
12	My daily life is full of things that keep me interested	1	2	3	4
13	I would be willing to describe myself as a "pretty strong personality"	1	2	3	4
14	I get over my anger at someone reasonably quick	1	2	3	4

Scoring the ER89 using the tertile method

20-38 =Low ego resilience

39–42 = Average resilience

43-56 = Above average resilience

## Appendix 7:

## Resilience Measure: The Resilience Questionnaire



Please read the statements below, and using the scale strongly disagree to strongly agree (1 – 5) indicate how the statement applies to your perception of yourself.

1	I have the knowledge and skills and experience to deal with almost anything that happens to me	1	2	3	4	5
2	I know what's important to me	1	2	3	4	5
3	I approach new situations with an open mind	1	2	3	4	5
4	When faced with new challenges, I am able to take control of the situation.	1	2	3	4	5
5	When I have a problem, I take time to define the problem before deciding what to do.	1	2	3	4	5
6	I have the capacity to laugh at myself.	1	2	3	4	5
7	I have a diverse network of good friends	1	2	3	4	5
8	I view change as an opportunity	1	2	3	4	5
9	I am able to think positively about myself when faced with challenges	1	2	3	4	5
10	When I look back I can see some clear patterns in my life about the types of choices I have made	1	2	3	4	5
11	I am able to adjust to changes	1	2	3	4	5
12	I start each day by working out what needs to be achieved during the day, and I end the day by reviewing what has been achieved, and what needs to be achieved on the next day	1	2	3	4	5
13	I perceive the problems and challenges of everyday life as challenges I can solve	1	2	3	4	5
14	I can empathise easily with others' frustrations, joys, misfortunes and successes	1	2	3		5
15	I find it easy to form lasting relationships and friendships	1	2	3		5
16	When an unwelcome change involves me I can usually find a way to make the change benefit myself	1	2	3	4	5
17	When I face difficult challenges I can maintain confidence in my own ability to overcome the challenges	1	2	3	4	5
18	I know what I want to achieve at work and in life	1	2	3	4	5
19	I can easily find ways of satisfying my own and other peoples' needs during times of change and conflict	1	2	3	4	5
20	I keep a 'to do' list, and use it every day	1	2	3	4	5
21	I try to find the cause of a problem before trying to solve it	1	2	3		5
22	During stressful and challenging times I can maintain effective relationships with those involved	1	2	3	4	
23	I share the frustrations in life, as well as the successes, with my friends	1	2	3	4	5
24	I am able to focus my energy on how to make the best of any situation	1	2	3	4	5
25	When I face challenges I look to myself to find ways of rising to the challenge	1	2	3		5
26	I know what I need to do to achieve my ideas for personal and professional achievements	1	2	3	4	-
27	I am able to accommodate other people's needs whilst focusing on achieving my own ambitions	1	2	3	4	5
28	When I am uncertain about what to do I write down the choices and my thought about them	1	2	3	4	5
29	When I solve problems I identify the links between the problems and other issues that may be around	1	2	3	4	5
30	I value the diverse experiences, skills and knowledge that others have in their interactions with me	1	2	3	4	5
31	I regularly participate with friends in social activities where I can relax	1	2	3	4	5
32	I believe my own decisions and actions during periods of change will determine how I am affected by the change	1	2	3	4	5

Contact: E: info@orghealth.co.uk T: 0845 833 1597

W: www.orghealth.co.uk

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### Scoring the Resilience Questionnaire

#### Instructions

Transfer the scores you gave to each item on the RQ in the appropriate box below (note the vertical listing of the statement numbers).

Then add the numbers in each row to calculate the score for each RQ dimension and enter it in the column to the right.

To determine your overall RQ score, add the numbers for all of the eight RQ dimensions and enter your total RQ score in the box at the lower right of the grid.

### Interpreting the scores

The maximum overall RQ Score is 160. The lowest possible overall RQ score is 32. For individual RQ dimensions, the maximum possible score is 20; the lowest possible score is 4.

Locate your overall RQ score in the range of RQ values below. Follow the suggestions offered in the explanations of each resilience level to begin developing and strengthening — or preserving — your personal resilience.

**141 to 160 Very Resilient:** You are consistently able to deal effectively with and even thrive on change. You have effective mechanisms in place that give you direction, structure, support and self-confidence.

**116 to 140 Resilient**: Most of the time you are able to deal with change in a positive manner. You have a number of mechanisms in place that help you deal with the uncertainty of change. You could strengthen your RQ by further developing your skills in your lower scoring RQ dimensions.

**61 to 115 Somewhat Resilient:** Change has a tendency to knock you off your best performance. You have some difficulty regaining your footing. While you have some stabilizing mechanisms in place, you could work at developing and exercising more of them. Look to your lowest scoring dimensions as a place to start.

32 to 60 Not Very Resilient: Change creates major challenges for you. You are frequently unprepared for the uncertainty and lack of stability that change creates. While there are times when you are able to find stability and focus, you need to develop and enrich a broad range of resilience capacities. Look to your lowest scoring dimensions as a place to start and then develop your RQ development plan.

Contact: E: info@orghealth.co.uk

T: 0845 833 1597

W: www.orghealth.co.uk

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